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Quality of Life and Palliative Care

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Marie Curie Cancer Care
Devoted to Life

The Royal Liverpool and Broadgreen University Hospitals NHS Trust

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Overview

- What is Palliative Care ?
- End of Life Care Into the Future
- Care of the Dying – Making a Difference

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What is Palliative Care ?

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WHO Definition of 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.

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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;

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WHO Definition of Palliative Care

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.

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'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)

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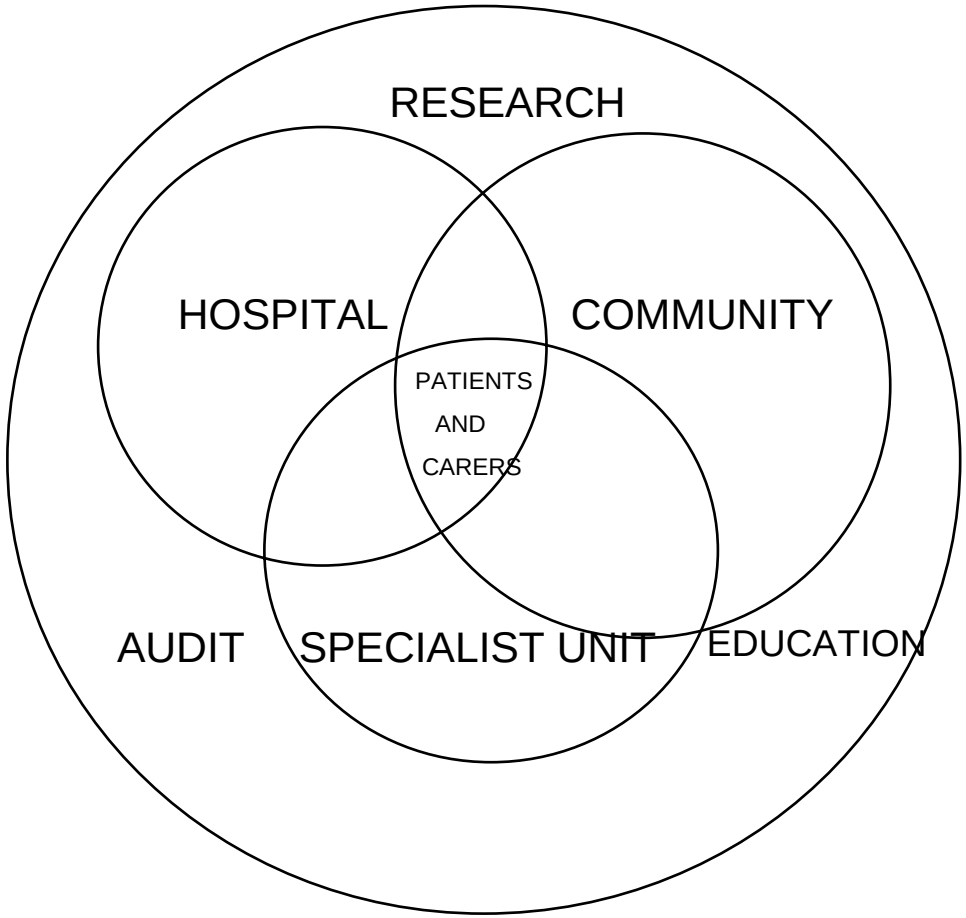
Model for Palliative Care



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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


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Marie Curie Hospice Liverpool

1. Inpatient services
2. OPD
3. Day Care
4. Bereavement service

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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

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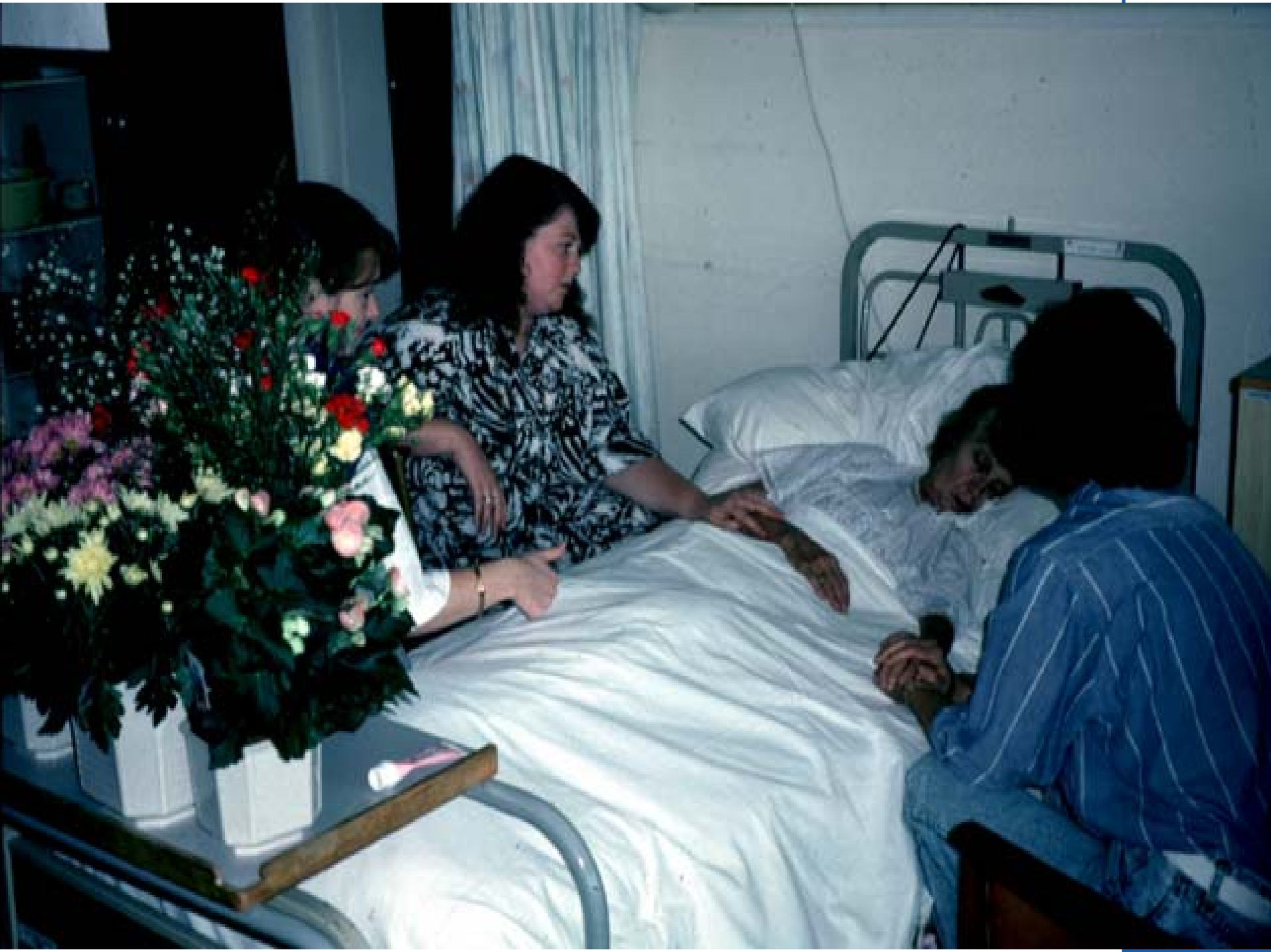
There’s nothing more we can do !



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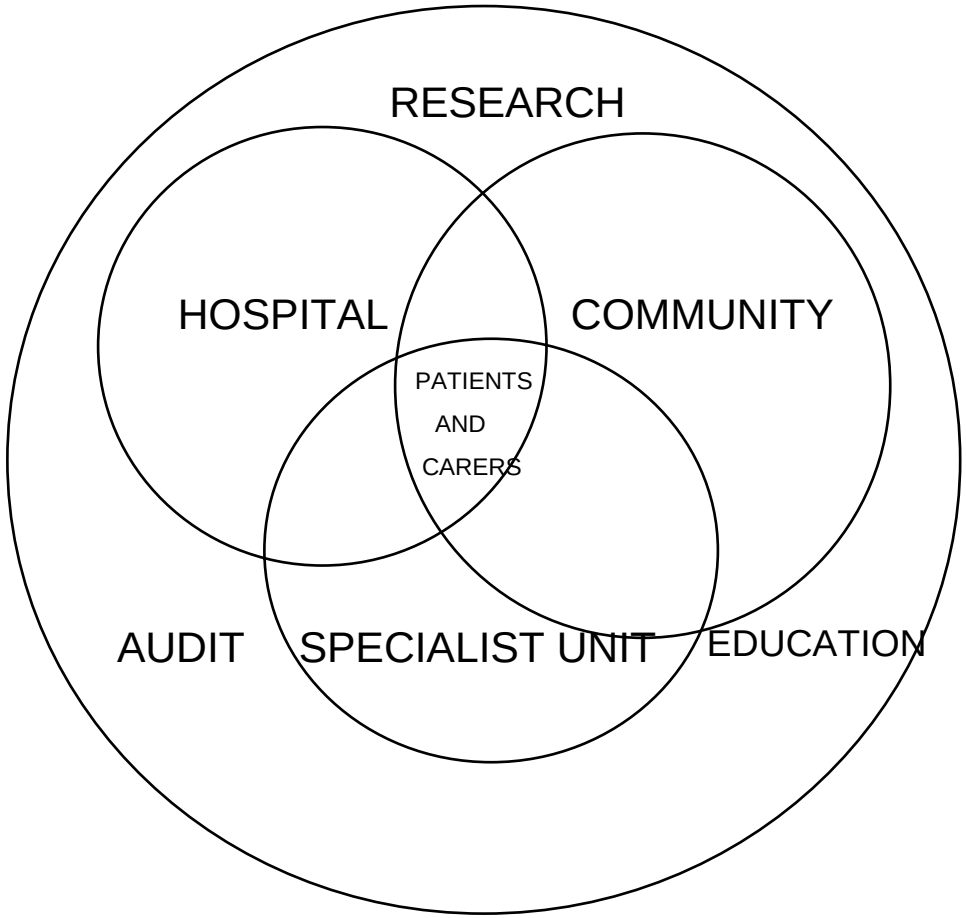

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Palliative Care Team Core

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

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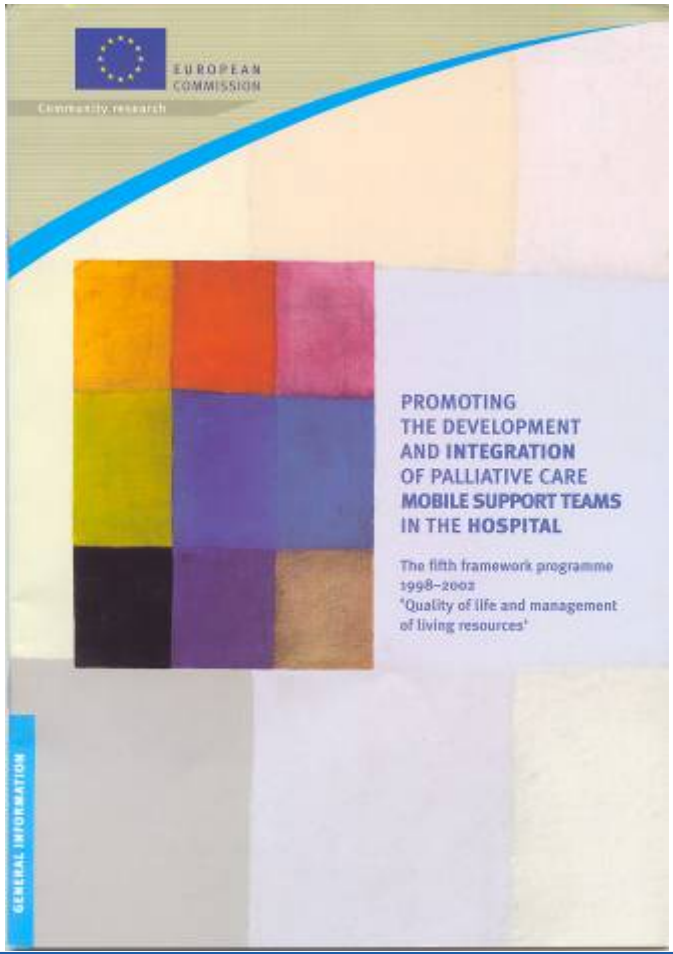
Summary of RLUH Palliative Care Team Activity 2005

<u>Demographics</u>

- Total number of referrals 720
- Median age 70 years
- 54% male 46% Female
- Non-cancer referrals 18%


EUROPEAN
COMMISSION
Community research
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'
GENERAL INFORMATION

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Three Phases of Development of a HMPCT Developmental Integrative and Sustaining

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

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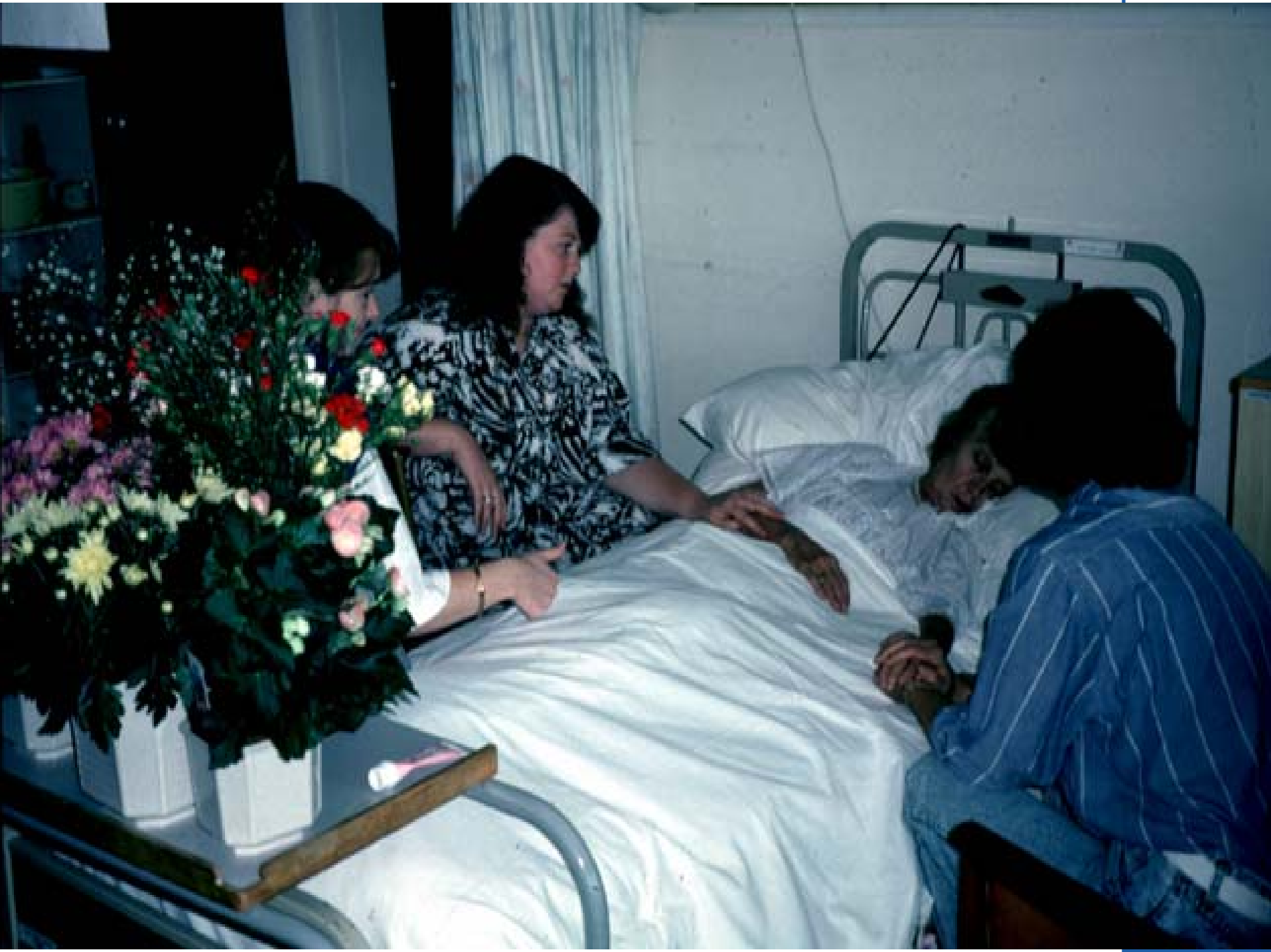

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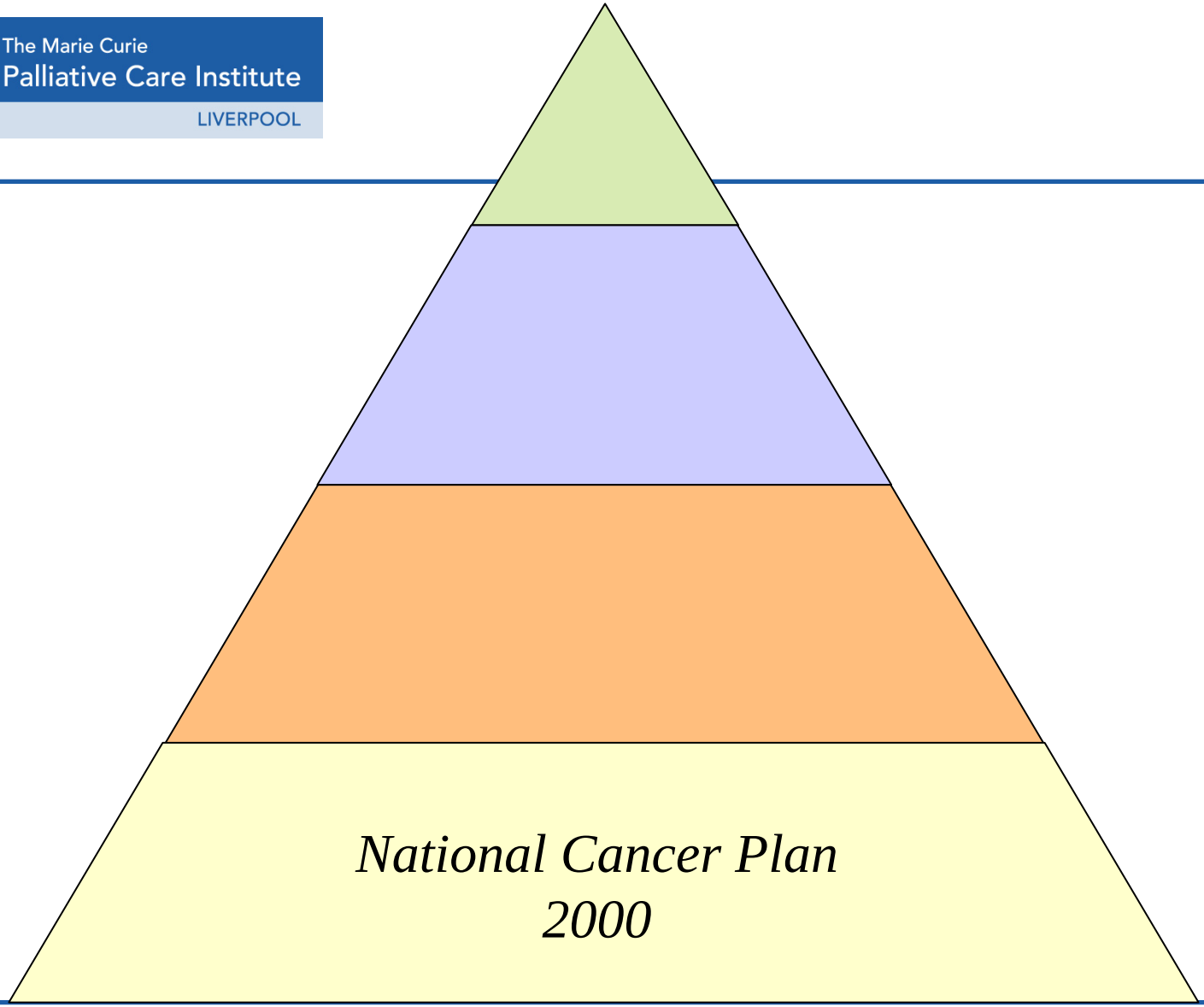

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The NHS National Cancer Plan

‘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’**

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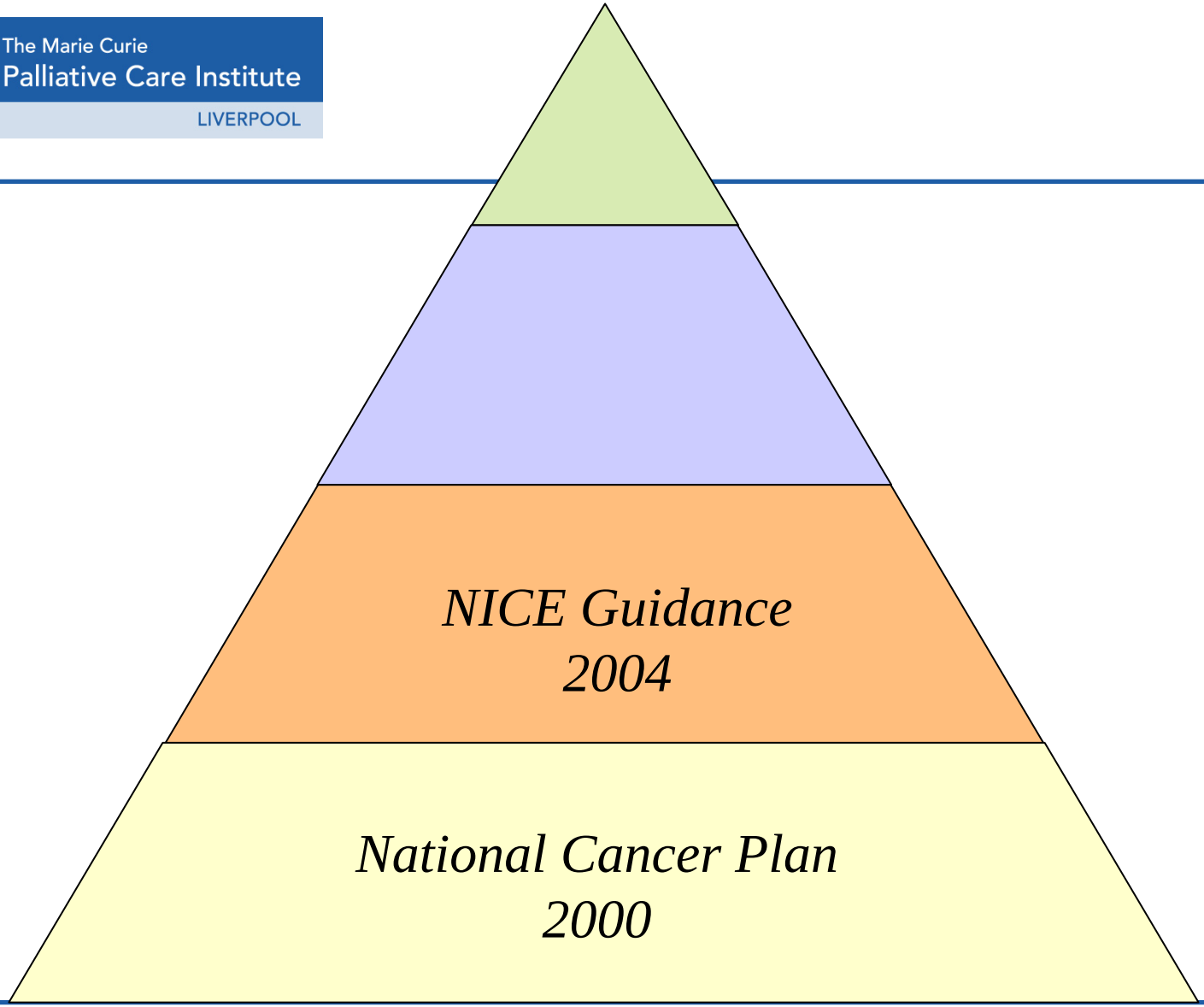

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NICE : Supportive and Palliative Care Strategy

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

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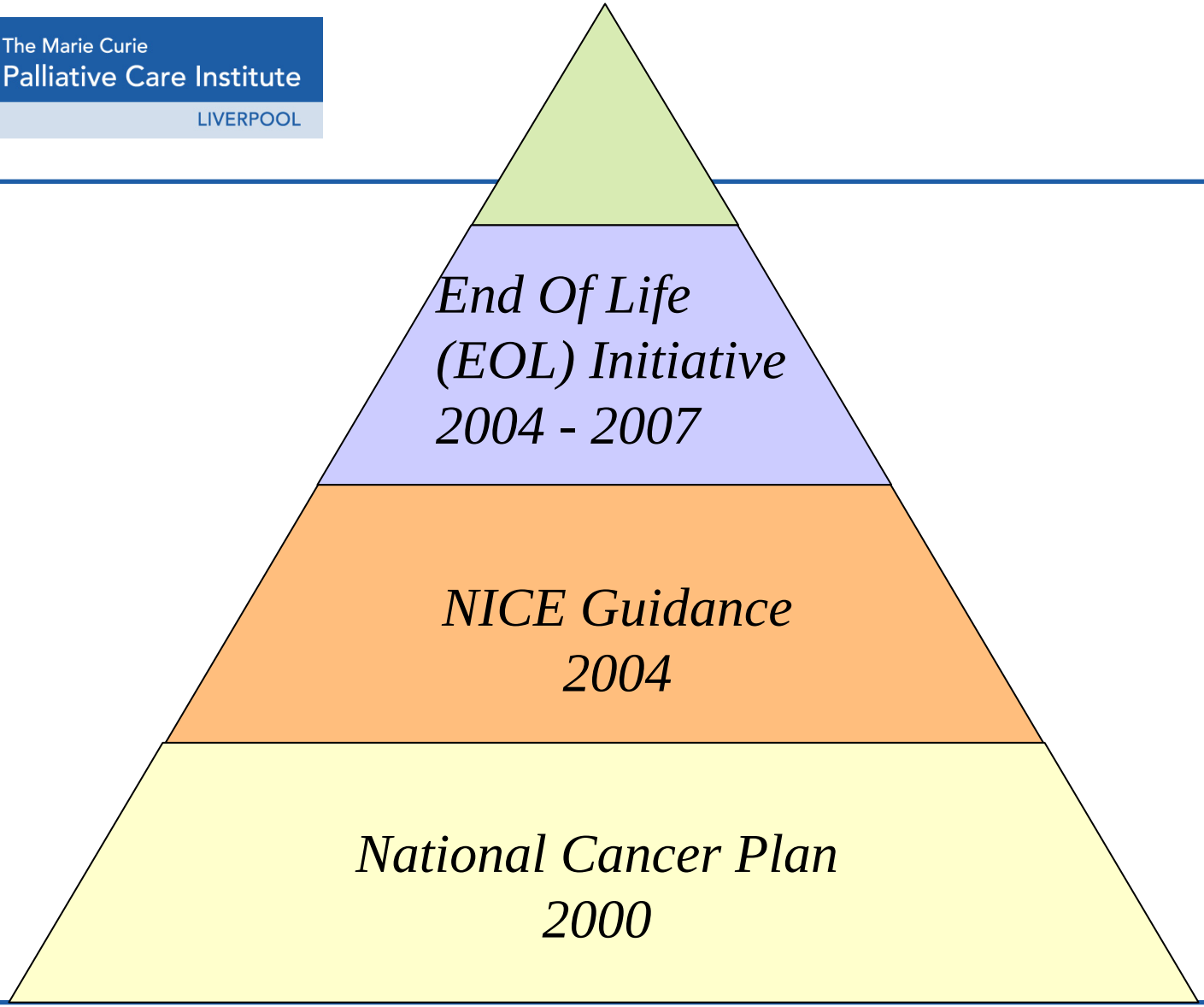

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Dept of Health : End of Life Care Programme

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


HM Government
DH Department of Health
Our health, our care, our say:
a new direction for community services
Health and social care working together in partnership
NHS

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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’

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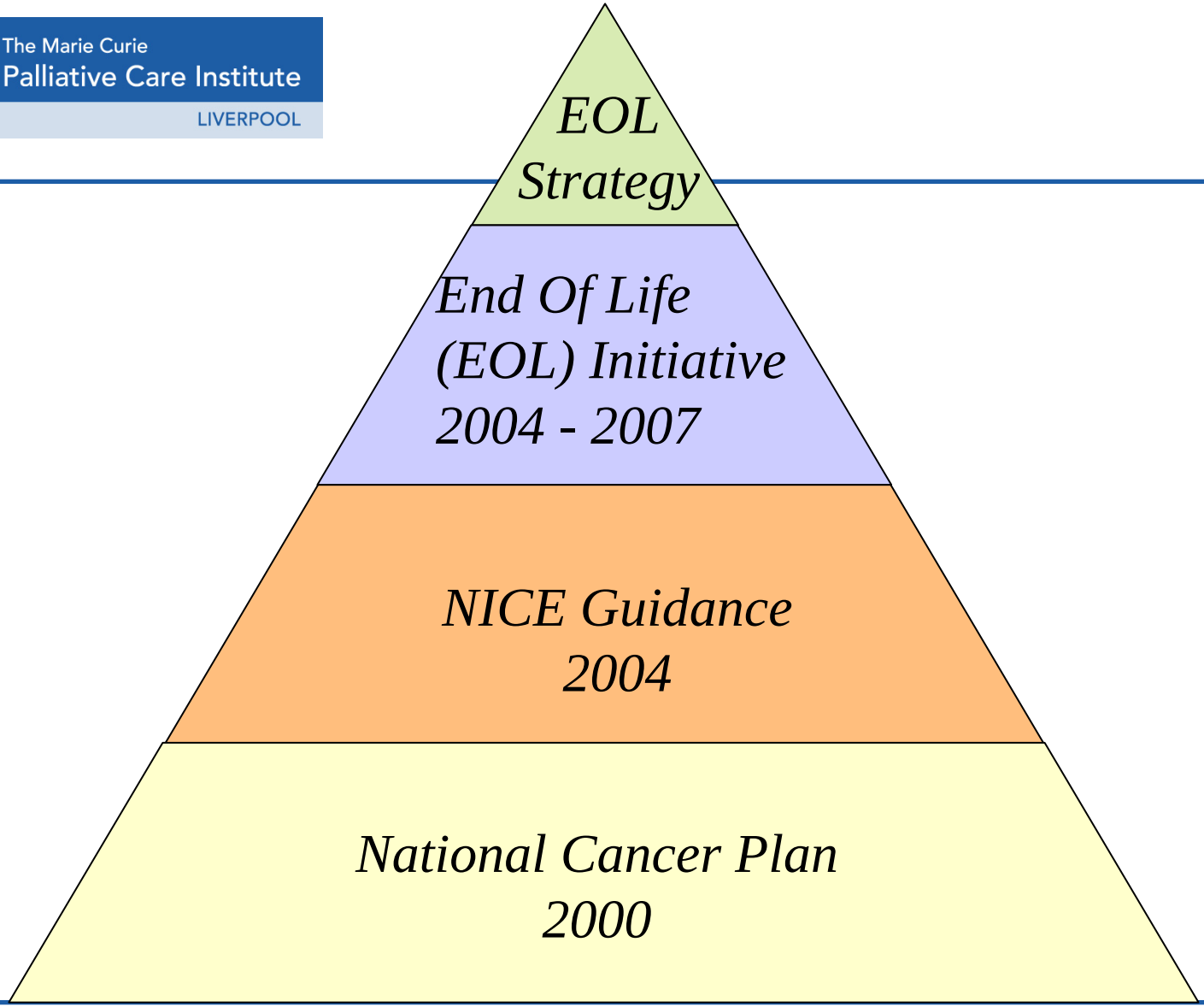

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End of Life Strategy

- All patients < 1 year prognosis
- Strategy to be produced autumn 2006
- Stakeholder event 5th October 2006
  - Key perspectives
  - 50 questions for discussion

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Three Key Perspectives

- Patient
- Service
- Societal

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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

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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

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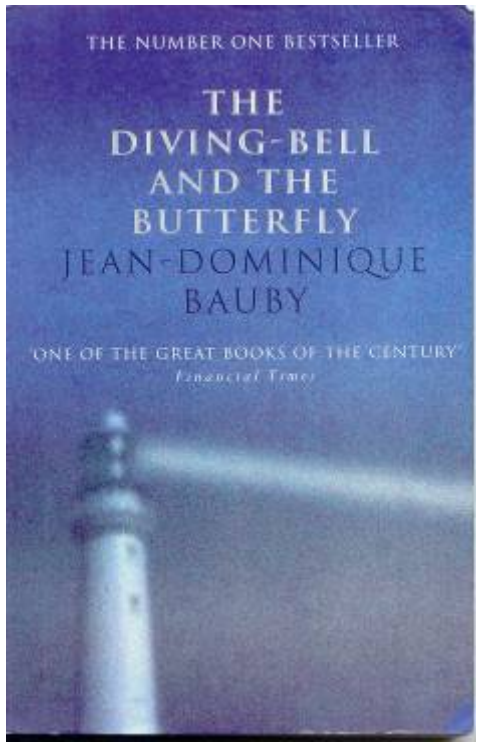
Meaning - Suffering



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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

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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

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Societal

- Death is unfamiliar
- Media is sensationalist
- Euthanasia and assisted dying debate
- Death not a ‘natural process’
- Preferences not openly discussed in society
- Demographics

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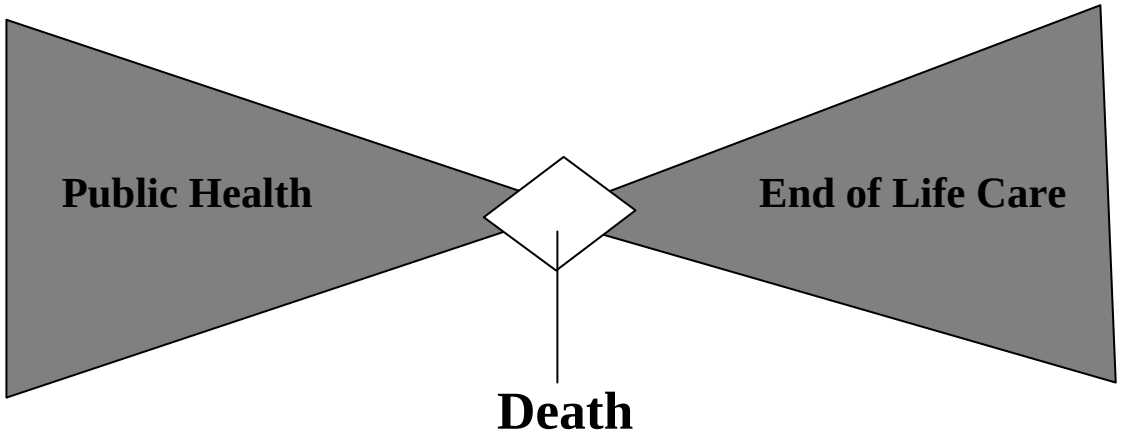
Charter for the Normalisation of Dying, Death and Loss (2005)



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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

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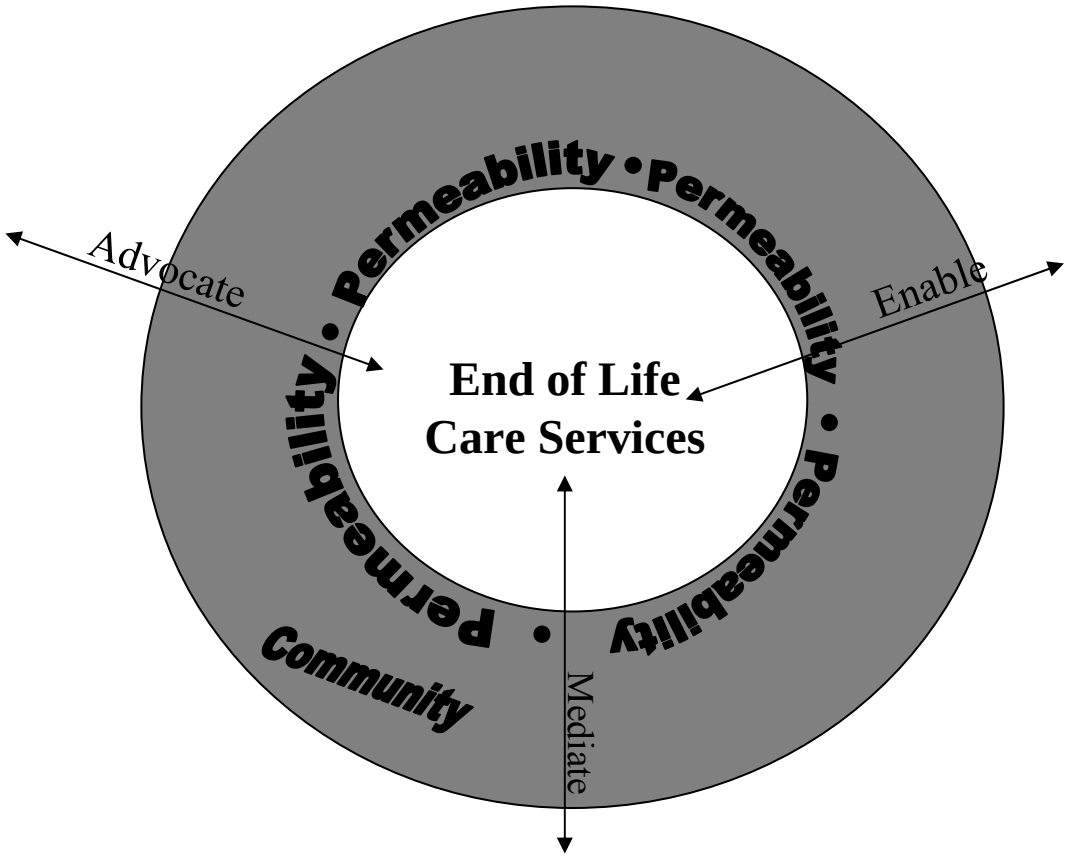

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Action Areas

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

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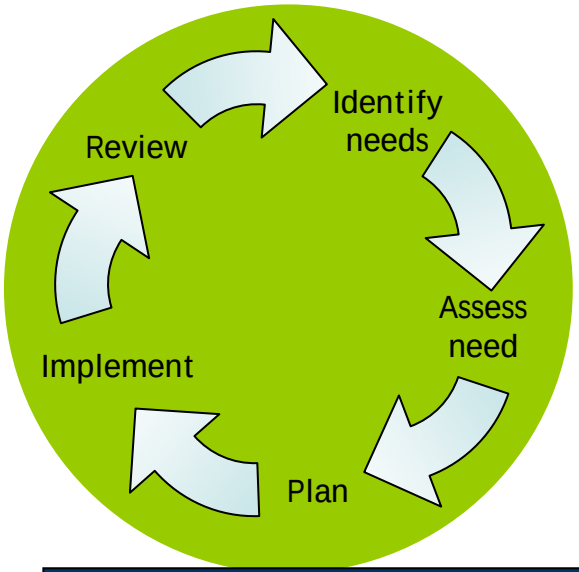
Patient Pathway



Advanced Care Planning (ACP)

Gold Standards Framework (GSF)

Liverpool Care Pathway (LCP)

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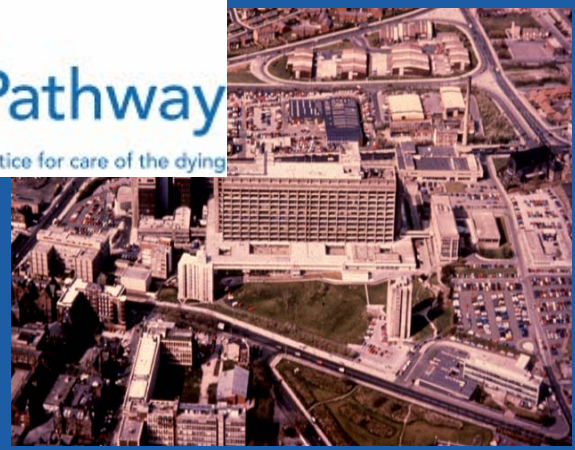
Liverpool Care of the Dying Pathway

LIVERPOOL
Care Pathway
Promoting best practice for care of the dying



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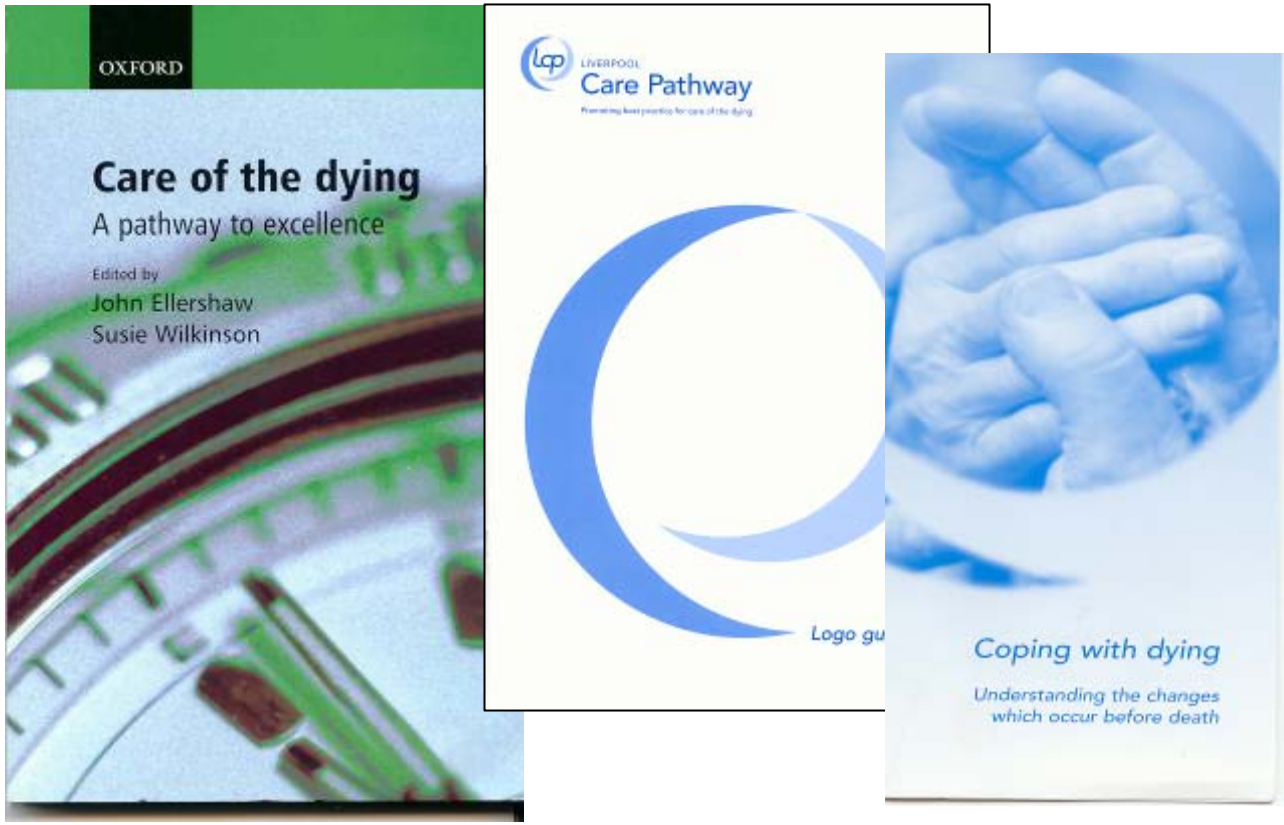

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Framework of LCP document

- **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

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What are the key goals for care of the dying ?

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Initial Assessment Goals

Goal 1.	Current medication assessed
Goal 2.	PRN medication prescribed
Goal 3.	Inappropriate interventions discontinued
Goal 4.	Patient ability to communicate assessed
Goal 5.	Psychological insight into condition assessed
Goal 6.	Religious needs assessed and met
Goal 7.	How family to be informed of death identified
Goal 8.	Relatives' facilities leaflet given
Goal 9.	GP practice contacted re: patient condition
Goal 10.	Relatives express understanding of care

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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

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Goal 2

PRN subcutaneous medication written up for list below as per protocol

(See sheets at back of LCP for guidance)

Pain	Analgesic Yes ☐ No ☐
Agitation	Sedative Yes ☐ No ☐
Respiratory tract secretions	Anticholinergic Yes ☐ No ☐
Nausea and vomiting	Anti-emetic Yes ☐ No ☐
Dyspnoea	Anxiolytic Yes ☐ No ☐

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Goal 3

Discontinue inappropriate interventions

Blood tests (including BM Monitoring)	Yes ☐ No ☐ N/A ☐
Antibiotics	Yes ☐ No ☐ N/A ☐
I.V.s (fluids/medications)	Yes ☐ No ☐ N/A ☐
Not for cardiopulmonary resuscitation recorded	Yes ☐ No ☐

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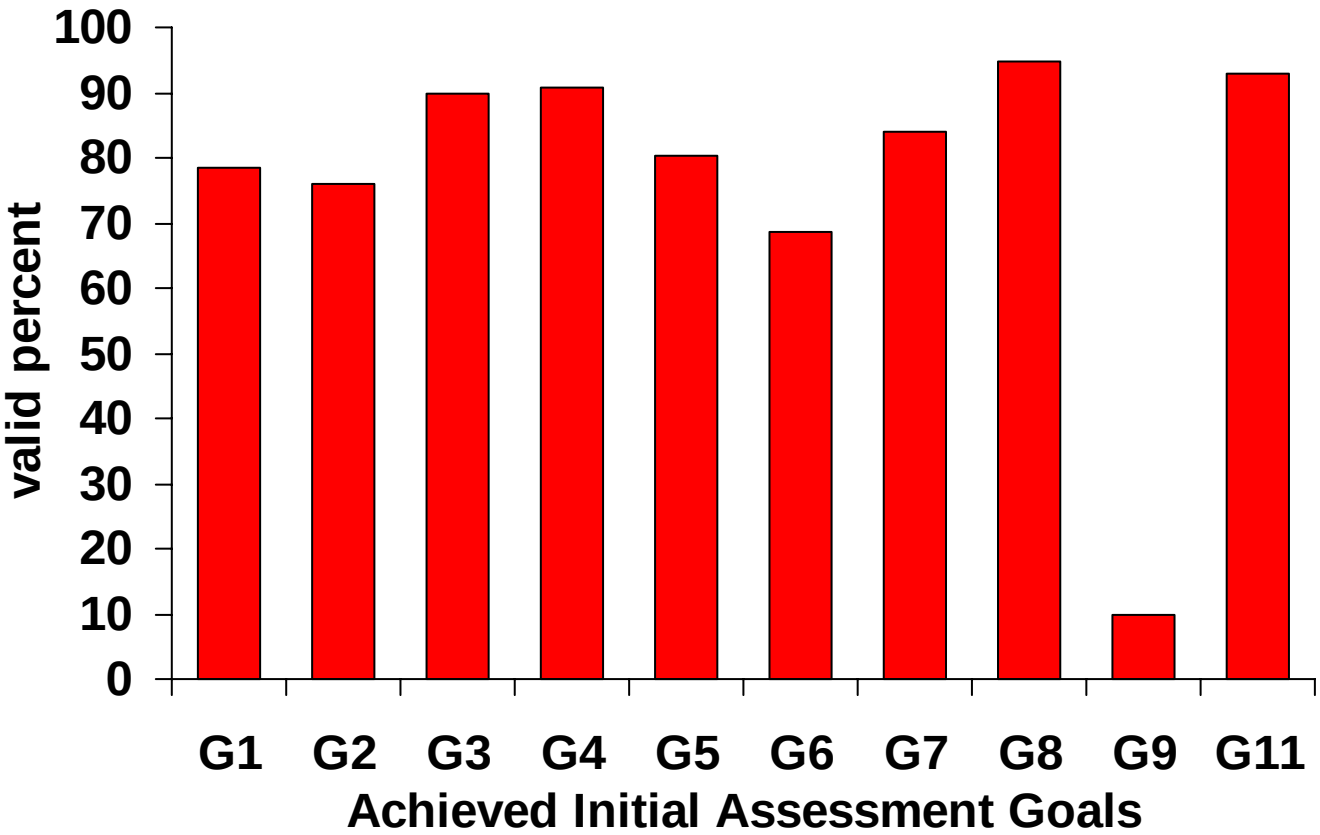
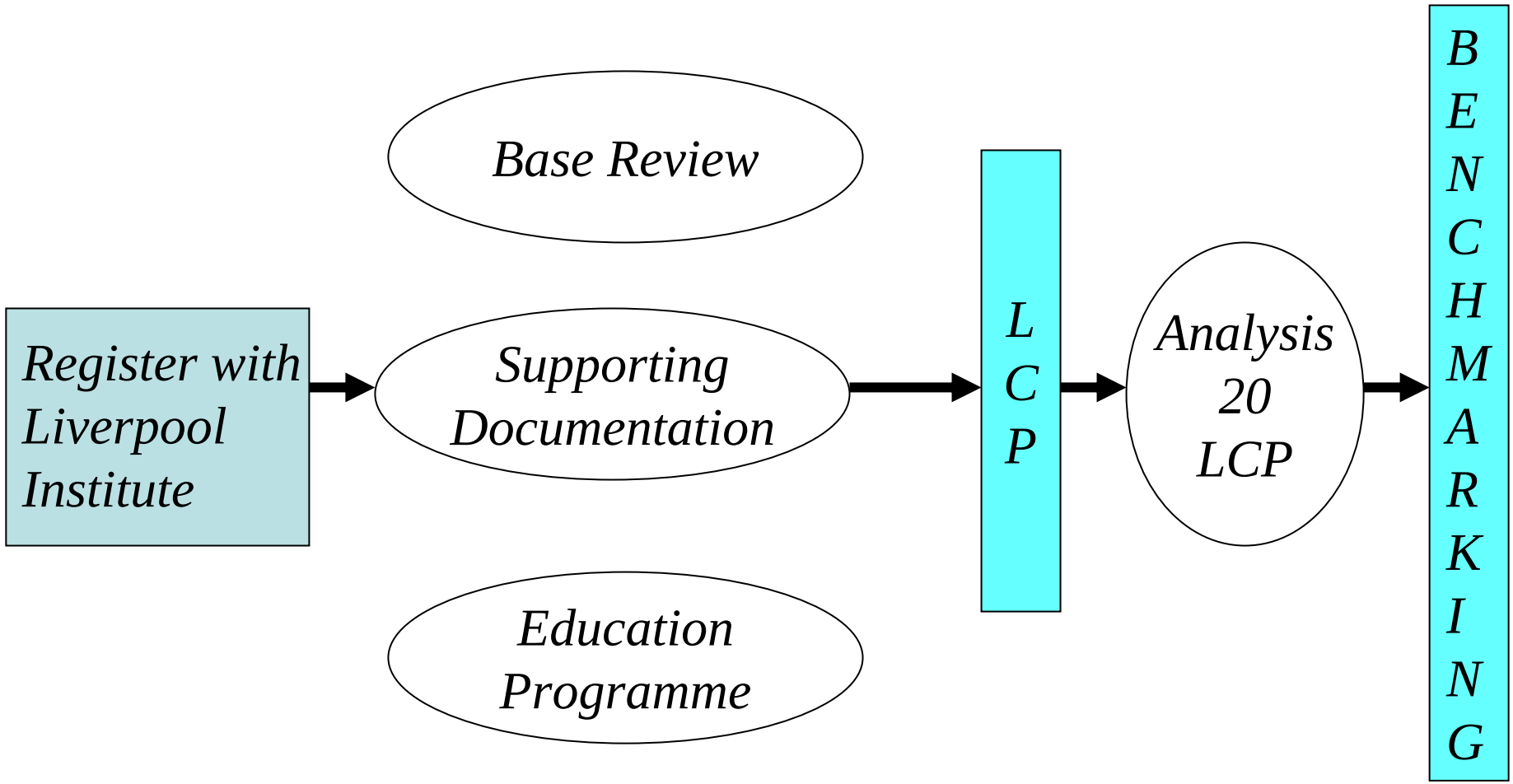
Hospital - Achieved Initial Assessment Goals.



LCP – Part of a Process of Change



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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

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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

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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

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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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