Palliative Care:
How can we make a difference?

Annual Conference 2009
Make a difference to the majority of people with palliative care needs: people with non-malignant conditions

Jacquelyn Chaplin: Project Manager: Palliative care for people with non malignant conditions
Aims

• To discuss how we can make a difference when we meet the palliative care needs of people with non malignant conditions

• Discuss the importance of assessment of need at a
  – strategic level
  – a local level
  – and an individual patient level
Influences
Remember the origins of palliative care – comfort and caring

- Sensitivity to individual need
- Not just about symptom management
- Value each patient as a unique human being who requires our care and compassion – holistic approach
- Sharing the journey – engaging with people at a human level
- Charismatic leadership
- A spirit of curiosity and discovery
Albert Einstein ....

- Learn from yesterday
- Live for today
- Hope for tomorrow
Non malignant conditions - palliative care needs may be different and different at different times

- Chronic Lung Disease
- Cystic Fibrosis
- Dementia
- Heart failure
- HIV/AIDS
- Huntington's Disease
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Parkinson's Disease
- Rheumatoid Arthritis
- Renal Failure
- Frail elderly with multiple co-morbidities
- Liver Disease
- Young Physically Disabled
- Cerebrovascular Disease
- Peripheral Vascular Disease

NB This list is not exhaustive
Different timescales

- Lung Cancer: Months – 1 year
- Breast Cancer: 3-8 years
- Severe COPD: 2-5 years
- Frail elderly/dementia: 6-10 years
Identifying palliative care needs of people with non malignant conditions – at a population level

Multi-dimensional approach

- Population based – analysis of epidemiological, demographic and socio-economic factors
- Comparative dimension – looking at relative need for cancer and non cancer related palliative care
- Stakeholder dimension – views of patients, carers, professionals and members of general public

Annual incidence of deaths and deaths per 100,000 population from cancer, non-cancer deaths and deaths from all causes by Health Boards and Scotland

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Population</th>
<th>*Annual Incidence Cancer Deaths</th>
<th>Cancer Deaths per 100,000 Population</th>
<th>*Annual Incidence Non Cancer Deaths</th>
<th>Non Cancer Deaths per 100,000 Population</th>
<th>*Annual Incidence All Deaths</th>
<th>*All Deaths per 100,000 Population</th>
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Data source: GRO (Scotland) – * Figures represent average for 6 years 2003-2008  2008 Figures are provisional.
Cancer and non cancer deaths

Estimates of number of people with palliative care needs

Symptom estimates
Cancer – 84% pain, 47% breathing difficulties, 38% depression
Non cancer - 67% pain, 49% breathing difficulties, 36% depression  
(Cartwright, 1991; Koffman et al, 2008)
Causes of death NHS Greater Glasgow and Clyde

Source: GRO (S) Annual Mortality Data 5 year average 2003-2007
<table>
<thead>
<tr>
<th>Place of death</th>
<th>Preferred place of death*</th>
<th>Actual place of death – cancer NHS GGC</th>
<th>Actual place of death – non cancer NHS GGC</th>
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</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>11%</td>
<td>49%</td>
<td>61%</td>
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<tr>
<td>Care Home</td>
<td>4%</td>
<td>6%</td>
<td>15%</td>
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<tr>
<td>Hospice</td>
<td>24%</td>
<td>21%</td>
<td>1%</td>
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<tr>
<td>Home</td>
<td>56%</td>
<td>23%</td>
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</table>

*Data Source: Priorities and Preferences for End of Life Care in England, Wales and Scotland, National Council for Hospice and Specialist Palliative Care Services (2003)

Data source: GRO (Scotland) – Figures represent average for 6 years 2003-2008. 2008 Figures are provisional.
Complexities of preferences regarding place of care and place of death and advance care planning

- Most data relate to people with cancer
- Preference re place of care is different from preference re place of death
- Differences between preference of patient and preference of family carer
- Changes in preferences over time
- Dying at home not as important as other factors e.g. freedom from pain, not dying alone, dignity and respect
- What is the optimum way and time(s) when preferences should be elicited, and by whom – recognise that not talking about death is a way of coping for some people
- Variable access to services
- Ethical issues of asking patients their preferences and not having the resources available locally to achieve that preference

(Steinhauser et al, 2000; Grande et al, 2003; Thomas et al, 2004; Gott et al, 2004; Brazil et al, 2005; Clayton et al, 2005; Taylor, 2006; Gomez and Higginson, 2006; Barclay and Arthur, 2008; Costantini, 2008; Grande and Ewing, 2008).
Palliative care needs at a local level

- Relative needs within a local area need to be considered – variations in life expectancy, deprivation, key health issues.
- Identify local priorities and address these via disease specific planning groups/ Managed Care Networks, local strategies, collaborative approach.
- Deprivation – areas of intense deprivation may require up to twice the community palliative care resources needed elsewhere.
- Recognising that many people will continue to die in hospital and therefore the quality of palliative care in hospital is very important.
- Recognising and planning the contribution of hospital palliative care teams - the structure and composition of hospital palliative care teams should take account of number of beds, in patient episodes of care and number of deaths.

(Clark, 1997; Soni et al, 1997; Higginson & Jarman, 1997; Koffman, Harding & Higginson, 2008; Morrison, 2008)
Different conditions – different models

Model of palliative care for frail elderly people and those with dementia

- **Big question** whether as a society we ensure that our older citizens receive the palliative care services and care that they require?
  - Frail elderly especially those with multiple co-morbidities – ‘surprise question’ is of questionable value
  - Recognise some elderly people fear what will happen to them at the end of life especially those who live alone – influences need
  - Dying at home is not always a priority – living at home independently as long as possible may be
  - The key - identify changing palliative care needs - respond appropriately including planning ahead - results in good care – regardless of how close to the end of their life the person is
  - Dementia – needs for advance care planning years in advance of palliative care need
  - Most people with dementia die in care homes – as a priority - support care homes to recognise changing need and respond appropriately
  - Ensure excellent care in last days of life in all care settings – e.g Liverpool Care Pathway for the Dying supported by appropriate education and training

(Gott, 2004; Gomes and Higginson, 2008; Grande et al, 2006; Gott, 2008; Barnes et al 2008; Scottish Commission for the Regulation of Care, 2009)
Different conditions – different models

Model of palliative care for people with chronic lung disease and/or heart failure organ failure

- Identification of changing need – whole system approach - primary care, acute services, disease specific CNS’s, specialist palliative care
- Recognition that palliative care needs may be intermittent – need an intermittent model of intervention that can be withdrawn if no longer required
- Ensure system in place to identify changing palliative care needs - key role of Clinical Nurse Specialists
- When admitted to hospital - at every admission reviewed by a consultant who knows them
- Focused specialist palliative care interventions to enhance quality of life e.g. breathlessness and fatigue management, information re financial support, complementary therapies etc
- Excellent care in last days of life

(Gott, 2004; Gott, et al 2007; Grande et al, 2006; Gott, 2008; Barnes et al 2008; Glare et al, 2008)
Different conditions – different models

Model of palliative care for people with long term relapsing debilitating illnesses e.g. muscular dystrophy, cystic fibrosis, multiple sclerosis

- Recognition that palliative care needs may be intermittent
- May need focused specialist palliative care interventions to enhance quality of life – pain management, breathlessness management, day services, focused services e.g. for young adults
- May also need intermittent respite services, carer support, bereavement support etc
- Excellent care in last days of life and ongoing support for families
Hope for the future

Dual approach
- Focus on specific diseases – across care boundaries – share successes
  - Chronic Lung Disease
  - Heart Failure
  - Cardiovascular disease
  - Liver disease
- Focus on frail elderly/ dementia – complexities of multiple disease processes
  - Home
  - Care homes
  - Hospital
    - acute,
    - medicine for the elderly
    - elderly psychiatry
- Recognising the key role of primary care team
- Collaborative working
  - Co-ordination across care settings
- Building on what works
  - Gold Standards Framework
  - Advance care planning
  - Symptom management
  - Liverpool Care Pathway for the Dying
- Working on issues that are pertinent to high quality palliative care regardless of diagnosis
  - Out of Hours
  - Respite
  - Carer support
  - Nursing / social care integration
  - Bereavement support
  - Access to complementary therapies
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Hope for the future…

- In the community – GP and District Nurse are key –
  - Integration of nursing and social care for people with palliative care needs
  - Integration of out of hours services
- In care homes – recognition of changing need, proactive planning
- In hospital setting
  - Supporting care with dignity, respect and compassion
  - Clinical leadership of charge nurse in relation to palliative care
  - Education of all staff - holistic approach
- In hospices
  - Educative consultative role
  - Care giving role
  - Out of hours support
In summary

- **Strategic level**
  - assessment of population need
  - integration with long term conditions and disease specific strategies, guidelines etc - included in ‘Gaun Yersel’, SIGN Heart Failure and NHS QiS Clinical Standards for COPD
  - palliative care not included in
    - SIGN 108 Management of patients with Stroke
    - SIGN 89 Peripheral arterial disease
    - SIGN 86 Management of patients with Dementia

- **At a local level**
  - ensuring local disease specific strategic plans and implementation plans include palliative care
  - ensuring access to local services meets local need

- **At an individual level** – accepting uncertainty – palliative care
  - Not about prognosis, time or length of survival
  - Recognising changing need, the speed of that change and responding to that and anticipating what may happen next
  - Person centred holistic compassionate care – we are more than ‘flesh and blood’
‘You matter because you are you and you matter until the last moment of your life.

We will do all you can not only to help you die peacefully but also to live until you die.’

Make a difference to the majority of people with palliative care needs: people with non-malignant conditions

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