Collaborative models of primary and secondary care at the end of life

“Ending together”

Khoo Teck Paut Hospital, Singapore, November, 2011

Professor Scott A Murray
St Columba’s Hospice Chair of Primary Palliative Care
Primary Palliative Care Research Group, University of Edinburgh

www.chs.ed.ac.uk/gp/research/ppcrg.php
World Mortality Rate

2005: 100%
2006: 100%
2007: 100%
2008: 100%
Death is part of the human condition.
5 key challenges in palliative care development

1. All illnesses
2. Earlier than later
3. All dimensions
4. All settings
5. All cultures
Models of co-ordination

- Co-ordinators or Key workers
- Shared care or partnerships
- Integrated care pathway eg LCP
- Managed clinical networks
- Frameworks eg GSF
- Programmes
- Collaboratives eg quality improvement
Co-ordination among

- Patients and family carers
- GPs and polyclinics
- Hospitals
- Hospices
- Residential homes
- Housing, lawyers
Synchronous or writing

- Hospice
- GPs
- Polyclinics
- Residential homes
- Housing lawyers
- Patient and family

hospitals
5 key challenges in collaborating at End of Life

1. All illnesses  
2. Earlier than later  
3. All cultures  
4. All settings  
5. All dimensions

Organ failure

GP has 20 deaths per list of 2000 patients per year

Acute

Dementia, frailty and decline

Cancer

Many years

Weeks, months, years

Death

Months or years

Death

Function

High

Low

Function

High

Low

Function

High

Low
Organ failure trajectory
Frailty trajectory
Figure 2. Indicative number of patients needing supportive/ palliative care at any point in time, per average GP.

Practice might have 18 patients/full time GP on the supportive and palliative care register.
Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study

Hilary Pinnock, senior clinical research fellow,1 Marilyn Kendall, senior research fellow,2 Scott A Murray, St Columba’s Hospice chair of primary palliative care,2 Allison Worth, senior research fellow, research manager,1 Pamela Levack, consultant in palliative medicine,3 Mike Porter, senior lecturer,4 William MacNee, professor of respiratory and environmental medicine,3 Aziz Sheikh, professor of primary care research and development1
When is pall care appropriate?

When to start collaborating

- When patients may benefit
- How to identify?
- Triggers
- Clinical status
- Admission to care home
- Patient request
Appropriate care near the end of life: from disease modifying to active palliation.

Palliative care: generalist and specialist

- Curative care
- Family carer and GP “jollying along”
- Diagnosis of life threatening illness
- Bereavement care

29% primary palliative care
Caring for people with organ failure

Stage 1  Physically well: Chronic Disease Management
Stage 2  Active supportive and palliative care: Gold SF
Stage 3  Terminal care: Liverpool care pathway
### SPICT: supportive and palliative care indicator tool

<table>
<thead>
<tr>
<th>Supportive &amp; palliative care indicators tool</th>
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</thead>
</table>

#### 1. Ask

| Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness? | Yes |
| Would you be surprised if this patient died in the next 6-12 months? | No |

#### 2. Look for one or more general clinical indicators

- Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.
- Patient has continued to lose weight (>10%) over the past 6 months.
- Patient has had two or more unplanned admissions in the past 6 months.
- Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.

#### 3. Now look for two or more disease related indicators

<table>
<thead>
<tr>
<th>Heart disease</th>
<th>Respiratory disease</th>
<th>Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>NYHA Class IV heart failure, severe valve disease or extensive coronary artery disease.</td>
<td>Severe airways obstruction (FEV₁&lt;30%) or restrictive deficit (vital capacity &lt; 60%, TLCO &lt;40%).</td>
<td>Performance status deteriorating due to metastatic cancer and/ or co-morbidities.</td>
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<tr>
<td>Meets criteria for long term oxygen therapy (PaO₂ &lt; 7.3).</td>
<td>Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.</td>
<td></td>
</tr>
<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
<td>Breathless at rest or on minimal exertion between exacerbations.</td>
<td>Neurological disease</td>
</tr>
<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
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</tr>
</tbody>
</table>
Scottish Palliative Care DES evaluation

- 29% of people on GP register before they die
  - 68% with cancer were on register at death
  - 20% with organ failure
  - 20% with frailty

- If on register likely to die at home, (25% hospital deaths)
- If not on register, likely to have hosp death
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<thead>
<tr>
<th>Request Date</th>
<th>Patient Number</th>
<th>Specimen</th>
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<th>Requestor</th>
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<td>UE</td>
<td></td>
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<td>G.P.Requested</td>
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**Alerts:** 4
This patient fulfils SPICT criteria for **Supportive and Palliative Care**

However **specific acute interventions** may still be appropriate to **improve comfort and quality of life**.

Some examples: **investigations to inform clinical management decisions, antibiotics, diuretics, clinically assisted nutrition and hydration, blood transfusion, palliative chemotherapy and radiotherapy, palliative surgery**.

Discuss clinical management with patient (or if not possible their representative):-

- Focus of **improving comfort and quality of life** potential benefits of specific acute interventions balanced with possible risks, harms or burdens
- Does patient have an **Advance Care Plan**?
- Does patient have a **registered Lasting Power of Attorney** for personal welfare decisions

Advance Care Planning information on [UHCW Palliative Care Team department intranet pages](#)
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Advance Care Planning information on [UHCW Palliative Care Team](https://intranetpages) [UHCW Palliative Care Team]

### Look for 2 or more general clinical indicators:

- Performance status poor (limited self-care, in bed or chair for over 50% of day) or deteriorating.
- Unplanned weight loss (5 – 10%) over the past 3 – 6 months and/or body mass index < 20.
- 2 or more Unplanned Admissions in past 6 months.
- A new event or diagnosis that reduces life expectancy.
- 2 or more advanced progressive illnesses (multi-morbidity).
- Symptoms that are severe, persistent, complex or difficult to control.
- Patient is in a nursing care home or NHS continuing care unit; or now needs more care at home.
This patient fulfils SPICT criteria for **Supportive and Palliative Care**

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<thead>
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<tr>
<th>2</th>
<th>Ask:</th>
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<tr>
<td>Please Select →</td>
<td>Would it be a surprise if this patient died in the next 6 – 12 months?</td>
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</tbody>
</table>
• www.palliativecareguidelines.scot.nhs.uk/careplanning/
3. Meeting all dimensions of need

<table>
<thead>
<tr>
<th>Physical</th>
<th>Psychological</th>
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<tbody>
<tr>
<td>Social</td>
<td>Spiritual</td>
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</table>

Grant E, Murray SA, Sheikh A. Spiritual dimensions of dying in different cultures. *BMJ* 2010;341:4859.
Dying is a 4-D activity

What’s happening with respect to other dimensions of need?

Method: meta-synthesis

• Thematically analysed in-depth serial interviews as case studies longitudinally and then cross-sectionally from a number of studies.

• Identified the presence and characteristics of social, psychological and spiritual needs
“living with uncertainty”

“great nurses and departments they are so caring”

“It was like a black hole”

“It’s much worse the second time round”

“You don’t know what is going to happen to you, fear is the worst thing”

Dyspnoea crises were multi-dimensional
Fluctuations of physical, social, psychological and spiritual wellbeing in family carers of patients with lung cancer

Application

• Can being aware of these trajectories help clinicians plan timely care to meet their patients multi-dimensional needs better, and help patients and carers cope
• Might this stop patients grasping at straws
• Seek realistic hope

• What do I really need to know about you, so I can care for you really well?

Chocheinoff
5 key challenges for services

1. All illnesses

3. All dimensions

4. All settings
Advance care planning interventions

- If things got worse, where would you like to be cared for?

Community hospice team

Primary care teams

Adopting patient-centred supportive care: possible questions
BMJ editorial, Murray March 2005

• What’s the most important issue in your life right now?
• What helps you keep going?
• What is your greatest problem?
• You usually seem quite cheerful, but do you ever feel down?
• If things got worse, where would you like to be cared for?
Out of Hours Care in Lothian
BJGP 2006
Electronic Palliative Care Summary

- Allows family physicians & Nurses to record in one place diagnosis, treatment, patients understanding & wishes,
- Anticipatory Care Plans, review dates
- Transmitted to out-of-hours services and A&E units daily
- Continuity of information
Mr JR 79 yrs

- Emphysema
- Bilateral basal bronchiectasis
- Ischaemic heart disease
- Vascular dementia
- Panic attacks
- Frequent admissions
Why no further admissions?

- Identified for supportive/palliative care
- Decided he would rather stay at home when ill
- DNAR form signed and left at home
- Placed on practice “palliative care register”
- Classified as a “gold patient”
- Regular contact to provide ongoing support
Scottish Nursing Homes project

- Admission to care homes triggers advance care planning
- Increase in DNAR status documented from 8 to 71% in patients who died
- Reduction of nearly 50% in inappropriate admissions to hospital
- Interviewed bereaved relatives reported better care

Lothian Health Board
Cultural competency

• Cultures
  – Truth telling
  – Traditional healers: most try to cure

• Religions and belief systems
  – Strength from relationship with God or from within
Health promoting palliative care

Living & Dying in Style

Dr. Eric Fairbank
The ABC and D of Dignity

- Attitude and assumptions
- Behaviour
- Compassion
- Dialogue

Dignity and the essence of medicine: The A, B, C and D of dignity conserving care

Chochinov  British Medical Journal 28 July 2007
Role of specialist palliative care

- Train and support generalist physicians and nurses in hospitals and the community
- Advocate for time and resources for palliative care in primary care throughout Europe
- Consider a service redesign of hospice care so specialist care is available according to need not diagnosis or prognosis
- Promote a discourse about death and dying in society
Service redesign: 4 main types of possible end of life developments to consider

<table>
<thead>
<tr>
<th>Inside</th>
<th>Outside</th>
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<tbody>
<tr>
<td>Sustaining innovation</td>
<td></td>
</tr>
<tr>
<td>Disruptive innovation</td>
<td></td>
</tr>
</tbody>
</table>

Dying for change. Leadbeater C, 2010, DEMOS
REGISTRATION

Online registration is available from the course website:

www.lifelong.ed.ac.uk/palliativecare

Payment can be arranged by invoice or secure e-payment by credit or debit card. To register by post or fax, please contact us (details below) to request a hard-copy registration form.

Full terms and conditions on the course website.

FEES

Standard Fee £575.00 GBP
Reduced Fee* £495.00 GBP

*Academic Institution / Charitable Organisation discount

The course fee includes:
- Comprehensive course notes
- Full daytime catering
- Certificate of completion from The University of Edinburgh

VENUE

The University of Edinburgh Medical School
Teviot Place, Edinburgh EH8 9AG, Scotland UK

The Medical School is part of the University's central campus situated in the heart of Edinburgh's Old Town. The area is within a short distance of Edinburgh Castle, Royal Mile and many restaurants, shops and hotels.

An interactive map is available on the course website.

Registered attendees will be sent joining instructions by email, three weeks before the course begins.

TRAVEL & ACCOMMODATION

Please note: Travel and accommodation is not included in the course registration fee and should be booked separately.

For further information and recommendations including maps, please visit the Edinburgh page of the course website.

www.edinburgh-inspiringcapital.com

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Edinburgh EH8 9LW
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fax: +44 (0)131 651 1746

www.spcare.bmj.com

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20 - 24 FEBRUARY 2012 EDINBURGH, UK

www.lifelong.ed.ac.uk/palliativecare
Programme

The programme consists of lectures, workshops and discussions with video presentations and support materials. The content focuses on the most current practice and policies of palliative care worldwide.

Programme topics include:

- An overview of the global research and development agenda for palliative care
- Review of illness trajectories and supportive/palliative care interventions
- Review of the range of clinical research issues, methodologies and tools for assessment of palliative care needs, interventions and evaluation
- Maximising e-health and innovative technologies to develop palliative care services and conduct research
- Understanding and integrating user perspectives across different disease trajectories and experiences of illnesses
- Experience of palliative care within different social, ethnic and faith communities
- Developing culturally and contextually appropriate research skills within palliative care
- Dignity therapy
- Health promoting palliative care

Course Contributors

The programme combines clinical research and data gathered first-hand by an ensemble of international specialists to provide the course with expert knowledge and skills; contributing to the support materials and delivery of the course content.

Prof Scott Murray  
St Columba’s Hospice Chair of Primary Palliative Care, The University of Edinburgh

Dr Liz Grant  
Dep. Director Global Health Academy, The University of Edinburgh

Prof Alex Jadad  
Centre for Global e-Health Innovation, Toronto University

Prof Harvey Chochinov  
Psychiatry and Palliative Care, University of Manitoba

Dr Mhoira Leng  
Director, Palliative Care Unit, Makerere University

Prof Julia Downing  
Makerere University & International Children’s Palliative Care Network

Prof David Clark  
School of Interdisciplinary Studies, University of Glasgow

Dr Marilyn Kendall  
Primary Palliative Care Research Group, The University of Edinburgh

Prof Marie Fallon  
St Columba’s Hospice Chair of Palliative Medicine, Edinburgh Cancer Research UK Centre & The University of Edinburgh

Dr Bridget Johnston  
Chair, UK Palliative Care Research Society & University of Dundee

Dr Bill Noble  
Editor-in-Chief, British Medical Journal Supportive & Palliative Care

About the course

This course provides an innovative approach to understanding palliative care, and insight into the current and future palliative care research agenda. It explores the value of different research methods, and identifies the opportunities and challenges in carrying out research with patients, carers and professionals in this sensitive area.

The course is dynamic and interactive, and presents the work and practice of many countries giving a wider perspective of palliative care within Europe and throughout the rest of the world.

Who is the course for?

This course is suitable for both palliative care specialists and also those who are generalists in palliative care, i.e. health practitioners such as GPs, geriatricians and other hospital clinicians, as well as public health and policy specialists whose work deals with palliative care either directly or indirectly.

The course will provide attendees with the necessary knowledge for assessing or reassessing current palliative care practice, benchmarking with international standards, and a vital understanding of different palliative care approaches to various illnesses and prognoses.

Example of course materials

Programme Topics

• An overview of the global research and development agenda for palliative care
• Illness trajectories and supportive/palliative care interventions
• Review of the range of clinical research issues, methodologies and tools for assessment in palliative care
• Understanding and integrating user perspectives across different disease trajectories and experiences of illnesses
• Palliative care within different social, ethnic and faith communities
• Maximising e-health and innovative technologies to develop palliative care services and conduct research
• Health promoting palliative care
• How to get published
5 key challenges in collaborating at End of Life

1. All illnesses
2. Earlier than later
3. All cultures
4. All settings
5. All dimensions
Models of co-ordination

- Co-ordinators or Key workers
- Shared care or partnerships
- Integrated care pathway eg LCP
- Managed clinical networks
- Frameworks eg GSF
- Programmes
- Collaboratives eg quality improvement