**Pearls in non-cancer palliative care management: trajectories and how to combine disease modifying and palliative care approach**

**Singapore, November, 2011**

Professor Scott A Murray  
St Columba’s Hospice Chair of Primary Palliative Care  
Primary Palliative Care Research Group, University of Edinburgh, UK  
[www.chs.ed.ac.uk/gp/research/ppcrg.php](http://www.chs.ed.ac.uk/gp/research/ppcrg.php)

Chair, International Primary Palliative Care Research group
Two sides of the one coin: curing and caring
5 key challenges for EoL care in next decade

1. All illnesses
2. Earlier than later
3. All dimensions
4. All settings
5. All nations and cultures
World Mortality Rate

- 2005: 100%
- 2006: 100%
- 2007: 100%
- 2008: 100%
Profile of People who die

Europe 1900
Age at death 46

Top 3 causes
- Infectious diseases
- Accident
- Childbirth

- Disability before death
  - Not much

Europe 2000
Age at death 78

Top 3 groupings
- Cancer
- Organ failure
- Frailty/ dementia

Disability before death
- Months - many years
1. Primary care can deliver palliative care for all in need.

GP has 20 deaths per list of 2000 patients per year

Organ failure

Acute

Cancer

Dementia, frailty and decline
“Acute decline” Trajectory

Onset of incurable cancer -- Often a few years, but decline often < 4 months

Cancer

Specialist palliative care available

Death

Function

High

Low

Time

Generally predictable course, short decline
Relatively well resourced hospice care fits well
Organ failure trajectory
Organ System Failure Trajectory

(high, lung, liver ... failure)

Frequent admissions, self-care becomes difficult

~ 2-5 years, but death usually seems “sudden”

Time

Needs: acute care for exacerbations, chronic care, support at home*

No service designed to routinely meet the needs of this pattern of decline

*No one seems to believe we have got this even half right. Delamothe T. BMJ 2009;338:b11457
Frailty trajectory
Dementia/Frailty Trajectory

Onset: deficits in activities of daily living, speech, ambulation

Time: Variable - up to 6-8 years

Needs: Integrated clinical care
Long term support at home, carer support, possibly nursing care.
Care homes with reliably good end-of-life care
Challenge for specialist palliative care is how to get involved with generalists in a redesign process to care according to needs.

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients:

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

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.
May 2008
BMJ poll: What area in medicine should be prioritised to make the most clinical difference to most people?

Care for all at the end of life
Scott A Murray and Aziz Sheikh
Palliative care beyond cancer

645  We're all going to die. Deal with it
646  Dying matters: let's talk about it
649  Recognising and managing key transitions in end of life care
653  Having the difficult conversations about the end of life
656  Achieving a good death for all
659  Spiritual dimensions of dying in pluralist societies
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

BMJ Feb 2011
Identify earlier rather than later.

Palliative care: what should happen: generalist and specialist

- Curative care
- Generalist palliative care
- Specialist palliative care
- Bereavement care
- Diagnosis of life-threatening illness
Palliative care: generalist and specialist

Curative care

Not yet identified
For palliative approach

Bereavement care

29%

Diagnosis of life threatening illness

primary palliative care
Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Stage 3  Terminal care

Sentinel events

Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Stage 3  Terminal care

- Sentinel events
- Care Plan
- Gold standards Framework
- Liverpool Care Pathway
- Death

Function

Time
When is a patient “palliative”?  

• Would you be surprised if Mrs A were to die within the next 12 months?  

• Study in cardiology ward revealed that this question identifies 60 - 70% of admissions  

• Avoid “prognostic paralysis” *  

**SPICT: supportive and palliative care indicator tool**

<table>
<thead>
<tr>
<th>Supportive &amp; palliative care indicators tool</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Ask</strong></td>
</tr>
<tr>
<td>Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness?</td>
</tr>
<tr>
<td>Would you be surprised if this patient died in the next 6-12 months?</td>
</tr>
<tr>
<td><strong>2. Look for one or more general clinical indicators</strong></td>
</tr>
<tr>
<td>Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.</td>
</tr>
<tr>
<td>Patient has continued to lose weight (&gt;10%) over the past 6 months.</td>
</tr>
<tr>
<td>Patient has had two or more unplanned admissions in the past 6 months.</td>
</tr>
<tr>
<td>Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.</td>
</tr>
<tr>
<td><strong>3. Now look for two or more disease related indicators</strong></td>
</tr>
<tr>
<td><strong>Heart disease</strong></td>
</tr>
<tr>
<td>NYHA Class IV heart failure, severe valve disease or extensive coronary artery disease.</td>
</tr>
<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
</tr>
<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
</tr>
</tbody>
</table>
Identifying patients for supportive and palliative care

Supportive & Palliative Care Indicators Tool

1. Ask
   Would it be a surprise if this patient died in the next 6-12 months? No

2. Look for two or more general clinical indicators
   - Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.
   - Progressive weight loss (>10%) over the past 6 months.
   - Two or more unplanned admissions in the past 6 months.
   - A new diagnosis of a progressive, life limiting illness.
   - Two or more advanced or complex conditions (multi-morbidity).
   - 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 III/IV heart failure, severe valve disease or extensive coronary artery disease.</td>
<td>Severe airflow obstruction (FEV1 &lt; 30%) or restrictive deficit (vital capacity &lt; 60%, transfer factor &lt; 40%).</td>
<td>Performance status deteriorating due to metastatic cancer and/or co-morbidities.</td>
</tr>
<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
<td>Meets criteria for long term oxygen therapy (PaO2 &lt; 7.3 kPa).</td>
<td>Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.</td>
</tr>
<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Breathless at rest or on minimal exertion between exacerbations.</td>
<td></td>
</tr>
<tr>
<td>Systolic blood pressure &lt; 100mmHg and/or pulse &gt; 100.</td>
<td>Persistent severe symptoms despite optimal tolerated therapy.</td>
<td></td>
</tr>
<tr>
<td>Renal impairment (eGFR &lt; 30 ml/min).</td>
<td>Symptomatic right heart failure.</td>
<td></td>
</tr>
<tr>
<td>Cardiac cachexia.</td>
<td>Low body mass index (&lt; 21).</td>
<td></td>
</tr>
<tr>
<td>Two or more acute episodes needing intravenous therapy in past 6 months.</td>
<td>More emergency admissions (&gt; 3) for infective exacerbations or respiratory failure in past year.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Kidney disease</th>
<th>Liver disease</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 4 or 5 chronic kidney disease (eGFR &lt; 30 ml/min).</td>
<td>Advanced cirrhosis with one or more complications:</td>
<td>Unable to dress, walk or eat without assistance; unable to communicate meaningfully.</td>
</tr>
<tr>
<td>Conservative kidney management due to multi-morbidity.</td>
<td>- intractable ascites</td>
<td>Worsening eating problems (dysphagia or dementia related) - now needing pureed/soft diet or supplements.</td>
</tr>
<tr>
<td>Deteriorating on renal replacement therapy with persistent symptoms and/or increasing dependency.</td>
<td>- hepatic encephalopathy</td>
<td></td>
</tr>
<tr>
<td>Not starting dialysis following failure of a renal transplant.</td>
<td>- hepatorenal syndrome</td>
<td>Recurrent febrile episodes or infections; aspiration pneumonia.</td>
</tr>
<tr>
<td>Now life limiting condition or kidney failure as a complication of another condition or treatment.</td>
<td>- bacterial peritonitis</td>
<td>Urinary and faecal incontinence.</td>
</tr>
<tr>
<td></td>
<td>- recurrent variceal bleeds</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Serum albumin &lt; 25 g/L and prothrombin time raised or INR prolonged (INR &gt; 2).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hepatocellular carcinoma.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not fit for liver transplant.</td>
<td></td>
</tr>
</tbody>
</table>

Try the SPICT

• [www.palliativecareguidelines.scot.nhs.uk](http://www.palliativecareguidelines.scot.nhs.uk)
• No copyright
• Hospital and community
In Scotland still not so good

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

• If on register, 25% chance of dying in hospital

• If not on register, 53% chance hosp death
Public and private accounts

• “I’m fine” – public account
• “Well actually, now you mention it…….” - private account
• Restitution versus realistic accounts
• 85% of people with life-threatening illness have both of these competing narratives in their heads

What do I need to know
3. Meeting all dimensions of need

- Physical
- Psychological
- Social
- Spiritual

Grant E, Murray SA, Sheikh A. Spiritual dimensions of dying in different cultures. *BMJ* 2010;341:4859.
Spiritual needs

• Everyone has them if faced with a serious illness
• Accepted definition used internationally relates to meaning and purpose of life
• People may or may not use religious vocabulary
• Such needs may cause distress and increase medical demand

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

*His old friends won’t even take a cup of tea with me now I’ve got cancer”* Mrs LR.
“living with uncertainty”

“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”

“great nurses and departments they are so caring”
Dyspnoea crises were multi-dimensional
Fluctuations of physical, social, psychological and spiritual wellbeing in family carers of patients with lung cancer

Awareness of these trajectories

- We can explain the likely course of the illness
- Patient and carers can understand what the future might hold
- We can plan timely 4-D care when needs expected, provide continuity through them
- Avoid futile physical treatment and expenditure

“The physician who can foretell the course of the illness is the most highly esteemed”. *Hippocrates*

Murray SA, Chinn DJ, Sheikh A  Access to psychological and psychiatric services needs to be improved for the dying  *JRSM* 2006;99(12):601
4. Potential of palliative care in primary care

- Over 50% would prefer to die at home
- But in UK 19% of people die at home
- Gold standards framework in >80% UK practices
- District frameworks Spain
- Kerela, India
International Primary Palliative Care Research Group
Role of this group since 2005

Advocacy for pall care in the community
  – Within specialist palliative care
  – Within primary care and secondary care

• Support and networking

• Encouragement of palliative care research in the community

• Building up evidence in primary care

Community based: care frameworks

Steps:
1. Identify
2. Assess
3. Plan
+ communicate
Advance care planning interventions

• What’s the most important issue in your life right now?
• If things got worse, where would you like to be cared for?

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 “supportive & palliative care register”
- Classified as a “gold patient”
- Regular contact to provide ongoing support
- Sadly finally admitted to die
Out of Hours Care in Lothian
BJGP 2006
Scottish Care 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
5 Primary care can provide care in lower income countries

Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries. *BMJ* 2003;326:368-72.
<table>
<thead>
<tr>
<th>Edinburgh, Scotland</th>
<th>Chogoria, Kenya</th>
</tr>
</thead>
<tbody>
<tr>
<td>main issue existential or spiritual distress</td>
<td>main issue physical suffering, especially pain</td>
</tr>
<tr>
<td>analgesia effective</td>
<td>analgesia unaffordable</td>
</tr>
<tr>
<td>anger in the face of illness</td>
<td>acceptance rather than anger</td>
</tr>
<tr>
<td>“just keep it to myself”</td>
<td>community support</td>
</tr>
<tr>
<td>spiritual needs evident but unmet</td>
<td>patients comforted and inspired by belief in God</td>
</tr>
</tbody>
</table>
Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. Grant E, Brown J Leng M, Bettega N Murray SA
BMC Palliative Care 2011, 10:8doi:10.1186
Approaching integration (n=4)
Localised provision (n=11)
Capacity building underway (n=11)
No hospice-palliative care activity yet identified (n=21)
Integrate pall care in primary care

• Curative plus preventive plus palliative
• Morphine prescribing by community nurses
• What are the basic palliative care skills needed in primary care internationally
palliative care 5 alls

1. All illnesses
2. All the time
3. All dimensions
4. All settings
5. All nations
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

Presented in partnership with the
BMJ Supportive & Palliative Care

1 year free access for course attendees

A new journal which connects many disciplines and specialties throughout the world by providing high quality, clinically relevant research, reviews, comment, information and news of international importance.

www.spcare.bmj.com

For all enquiries:
CPD Unit - Office of Lifelong Learning
The University of Edinburgh
11 Buccleuch Place
Edinburgh EH8 9LW
Scotland UK
email: CPD@ed.ac.uk
phone: +44 (0)131 651 1189 / 1180
fax: +44 (0)131 651 1746

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 detailed 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.

20 - 24 FEBRUARY 2012 EDINBURGH, UK
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
  Deputy 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 Falcon
  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

TRAJECTORIES OF WELLBEING AT THE END OF LIFE IN FAMILY CARERS

[Diagram showing wellbeing trajectories with labels for physical, social, psychological, and spiritual well-being over the stages of diagnosis, recurrence, terminal stage, and death]

Example of course material


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 an 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.
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 and in hospitals.
- Consider a service redesign so specialist care is available according to need not diagnosis or prognosis.
- Promote a discourse about death and dying in society.
Geriatrics

- >65 but most >80
- 25% of popn elderly
- Frailty, dementia, co-morbidities
- Functional, cognitive and social assessment 3D
- Culture rehabilitation
- 20% of I/P die
- Shorter consults

Palliative care

- Might die
- 1% at end of life
- Cancer but extending
- Physical, social psychological, and spiritual 4D
- acknowledging death
- 70% of I/P die
- Longer time
Service redesign: 4 main types of possible end of life developments to consider

<table>
<thead>
<tr>
<th>Inside</th>
<th>Outside</th>
</tr>
</thead>
<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
Sustaining inside = improving

• Better staff training to improve quality of service, LCP is a good example of this
• Identification of triggers for break point conversations would be another example
• Advance care planning
Sustaining outside = combining

• Co-ordination and collaboration among services by different agencies
• One example is appointment of navigators to find best mix of services
• Another - Active discharge planning in hospitals
• Federations of end of life service providers could encourage hospices to provide end of life care expertise and training for a group of local care homes –
• Integrated commissioning with social work
Disruptive outside = transforming

• Strengthen family capacity to care by dedicated “compassion benefits” as in Sweden
• Properly trained volunteer support network modelled e.g. Kerala in India
• Dedicated 24/7 specialist nursing support
• Dedicated end of life telephone helpline with friendly familiar knowledgeable people
• National hospice at home service
• Spread use of personal budgets at the end of life
palliative care 5 alls

1. All illnesses
2. All the time
3. All dimensions
4. All settings
5. All nations
Health promoting palliative care

Living & Dying in Style

Dr. Eric Fairbank
RCT early palliative care from diagnosis of lung cancer

- one can only speculate what made the early palliative care group happier and live longer.
- Was it comforting for patients to be listened to and to know that they would be well taken care of and their suffering would be relieved when it was their time to die.
- Was it that family members were reassured by open conversations about the end of life, leading to better care at home and they took time to really discuss the patient’s and family’s concerns.
palliative care 5 alls

1. All illnesses
2. All the time
3. All dimensions
4. All settings
5. All nations