Primary Palliative Care Task Force
Update 4, Lancaster, Oct 2013
Primary Palliative Care Research Group
A multi-disciplinary team with strong international links researching to improve end of life care in the community.

Professor Scott Murray explains the vision of the group in a 1 minute video

Primary care is well placed to undertake palliative care for patients
- with all life-threatening illnesses
- from early in the course of the illness
- with all dimensions of need
- in all settings
- in all countries
and to support carers through the journey of illness and bereavement.

Forthcoming events:
- 3rd International Public Health and Palliative Care Conference 2013
  The International Public Health and Palliative Conference has been growing in its number of participants since the first conference was held in 2009 in Kerry, Ireland. To this end, a further event is on the horizon for 2013. The 3rd International Public Health and Palliative Care Conference to be held in Limerick, Ireland between 25-27 April 2013.

- "Palliative Care: Making a Difference Internationally" a 5-day PICO course, will run from 18th-22nd February 2013. This week will feature a keynote address by Sir Harry Burns, Scottish Chief Medical Officer on resilience at the end of life on Thursday 21st February. Please see the learning website for more details and to register. See teaching page for details of our teaching work.

News and publications:
- Jubilee Honours for Professor Scott Murray:
  Professor Scott Murray has been awarded an MBE in the Queen’s birthday honours list for services to Medical Science. Congratulations Scott!

  See our key publications page for recently published papers.

With thanks to all our funders, including:

[Logos of various organizations]
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.spncare.bmj.com

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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.

18th to 22 Feb 13

www.edinburgh-inspiringcapital.com

www.lifelong.ed.ac.uk/palliativecare
International Primary Palliative Care Research Group

Prof Geoff Mitchell, University of Queensland, Australia
Prof Scott A Murray, University of Edinburgh, UK
Prof Fred Burge, Dalhousie University, Canada
Dr Eric van Rijswijk, UMC St Radbound University Hospital, The Netherlands
Dr Alan Barnard, University of Cape Town, South Africa
Role of the group

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 and development in the community

• Web resource
  http://www.uq.edu.au/primarypallcare

• Scott.Murray@ed.ac.uk
Advocacy in meetings

Quebec 2005
Cape Town 2010:  13\textsuperscript{th} - 14\textsuperscript{th} September 2010
Palliative care: Family physicians can research and treat

1. All diseases
2. All times - earlier rather than later
3. All dimensions
4. All settings
5. All nations
Opportunity 1: cancer and beyond


Organ failure

GP has 20 deaths per list of 2000 patients per year

Cancer

Acute

Dementia, frailty and decline
Opportunity 3: impacting on all dimensions

- physical
- psychological
- social
- spiritual
4 Community based: care frameworks

1. Identify

2. Assess

3. Plan

+ communicate
Strengthening and Integrating Palliative Care into national health systems in Kenya, Uganda, Rwanda and Zambia

Supported by British Government

2102-15 £1.5M
Palliative care in the community can treat and research

1. Cancer and life-threatening illnesses
2. Earlier rather than later
3. Holistic care – all dimensions
4. All nations
5. All settings
Vision

Scotland should be a society in which dealing with death, dying, bereavement and loss in a healthy and constructive way is seen as part of ordinary life and where members of the public and health and social care professionals and volunteers have awareness of these issues and the many ways in which communities and individuals can support each other.

Scott.murray@ed.ac.uk
• Health Promoting Palliative Care
• Carers
Taskforce Members

- Scott Murray, Scotland
- Eric van Rijswijk, Holland
- Nils Schneider, Germany
- Bart Van den Eynden, Belgium
- Xavier Gomez, Spain
- Trine Brogaard, Denmark
- Tiago Villanueva, Portugal
- Jurgen Abela, Malta
- Steffan Echmüller, Switzerland
- Geoff Mitchell, Australia
- Julia Downing, Serbia
- Libby Sullnow, England
Background

- Primary care is uniquely placed in the community to provide palliative care
- It is already providing much of the care for long term conditions
- Ongoing relationships facilitate physical, social, psychological and spiritual support
- Primary care teams require training and support to realise this potential
- Countries have variable primary care
Aims and Objectives

• Aim:
  – To help maximise the potential of primary care to provide quality last year of life care

• Objectives
  – To help develop the practice of palliative care in primary care
  – To develop guidelines for early palliative care for all trajectories and in the community
  – To develop links between specialist and primary palliative care and public health
Year 1 activity: 2012

Year 1: case studies from 20 European countries, and analysis of what factors promote and hinder primary palliative care in these countries.

Literature review as to components of good palliative care in the community. Scoping of any tools and ways patients are identified for palliative approach, and vocabulary used.

Produce a holding statement of the importance of primary palliative care.
Year 2 activity: 2013

Further international consultation process with Primary Care and Palliative care to produce
• guidelines for fast-forwarding palliative care in the community in European countries.
• Advocacy document for use at national level to promote palliative care in primary care
Countries with survey completed

Denmark
Albania
Armenia
Belgium
Germany
Ireland
Malta
Netherlands
Portugal
Serbia
Catalonia
Switzerland
UK
Ukraine
Spain
France
Luxembourg
Norway
Poland
Sweden
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Teaching

• Undergraduate: 15/20 countries have some form of undergraduate teaching

• All countries reported postgraduate training opportunities
  – Ranging from PhD/MSc/diploma to 2 day sensitisation programmes
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Development of Primary Palliative Care

• Do GPs keep a register of “palliative care patients”? Only 3/20

• Are any frameworks used? 4/20

• How are patients identified: usually not: if identified it is by hospital and primary care

• Percentage of cancer patients: average 80% but ranged from 19-95%

• All countries had specialist advice by phone, most via outpatient service or in the home and about half in a day centre
Terminology used

• No locally accepted European-wide terminology: some stigma of the term palliative care but few know it’s meaning.
• Current term used translates as ‘relief care’
• Taboo with the term ‘palliative’ but this is diminishing.
• Increasingly, the term ‘care of the critically ill and dying’ is used.
• Hospice care, palliative care, terminal care, supportive care and end of life care all used.
• Stigma exists around ‘hospice care’ as it is seen as somewhere people are abandoned and rejected and die.
• The terms palliative and hospice are not frequently used with patients as they are not understood.
Policy Developments

• Range including
  – Production of national standards (Albania, Armenia)
  – Action plan by Ministry of Health (Albania)
  – New identification tools in Belgium, Holland, Catalonia
  – Development of out of hours specialist advice (Denmark)
  – Legal right to palliative care in statute and ‘Charter for the critically ill and the dying’ (Germany)
  – National steering committee in Primary Palliative Care (Ireland)
  – National Plan for Palliative Care (Portugal)
  – National strategy for palliative care (Serbia)
  – National strategy for palliative care moving to community care (Switzerland)
  – End of Life initiative in UK gives financial incentives in primary care (UK) and specific incentives in Scotland
Some Barriers

• Lack of training, funding, resources and time
• Issues of bureaucracy, including around opiates
• Task distribution between specialist and primary care
• No reimbursement yet for palliative care services by insurance companies
• Poor handover out of hours
• Part of the population not yet covered by a GP
• Limitations of community nurse support
• Payment structure for GPs favours hypertension etc. over palliative care
Some Opportunities

• Increasing awareness of public, politicians and healthcare professionals of palliative care
• GPs could work to identify palliative care patients
• GPs well situated to provide good care
• National frameworks being developed
• Educational opportunities being developed
• Possibility of developing better working with community nurse services
Summary of suggested three steps for earlier identification

**Step 1**

Ask the Surprise Question

Would you be surprised if the patient were to die in next months, weeks or days?

- **NO**
  - Don’t Know
  - YES

**Step 2**

Do they have General Indicators of Decline?

- **YES**
  - Don’t Know
  - NO
  - Reassess regularly

- **NO**
  - Reassess regularly

**Step 3**

Do they have Specific Clinical Indicators?

- **YES**
  - Begin GSF Process
    - Identify: Include the patient on the GP’s GSF/QOF palliative care register or locality register if agreed. Discuss at team meeting.
    - Assess: Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.
    - Plan: Plan and provide proactive care to improve coordination and communication.
  - Reassess regularly

- **NO**
  - Reassess regularly
The SPICT™ is a guide to identifying people at risk of dying within the next 12 months.

**Lock for two or more general indicators of deteriorating health.**
- Performance status poor or deteriorating, with limited reversibility.
- Needs help with personal care, in bed or chair for 50% or more of the day.
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

**Look for any clinical indicators of advanced conditions**

**Cancer**
- Functional ability deteriorating due to progressive metastatic cancer.
- Too frail for oncology treatment or treatment is for symptom control.

**Dementia/ frailty**
- Unable to dress, walk or eat without help.
- Choosing to eat and drink less; difficulty maintaining nutrition.
- Urinary and faecal incontinence.
- Unable to communicate meaningfully; little social interaction.
- Fractured femur; multiple falls.
- Recurrent febrile episodes or infections; aspiration pneumonia.

**Neurological disease**
- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

**Heart/ vascular disease**
- NYHA Class III/IV heart failure, or extensive, unrelenting coronary artery disease with:
  - breathlessness or chest pain at rest or on minimal exertion.
- Severe, inoperable peripheral vascular disease.

**Respiratory disease**
- Severe chronic lung disease with:
  - breathlessness at rest or on minimal exertion between exacerbations.
- Needs long term oxygen therapy.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.

**Kidney disease**
- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure complicating other life limiting conditions or treatments.
- Stopping dialysis.

**Liver disease**
- Advanced cirrhosis with one or more complications in past year:
  - ducal resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleed
- Liver transplant is contraindicated.

**Assess and plan supportive & palliative care**
- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (e.g. with a primary care register).
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<thead>
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<th>Surprise question</th>
<th>Would you be surprised if this patient dies within 1 year?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need, demand and choice</td>
<td>Any request to limit the treatments or palliative care from patient, family, or team members?</td>
</tr>
<tr>
<td>• General clinical indicators (sustained, not related to acute intercurrent process)</td>
<td>Nutritional decline Weight / albumin</td>
</tr>
<tr>
<td>• Combined Severity AND Progression</td>
<td>Functional decline KPS or Barthel</td>
</tr>
<tr>
<td>• Conditions &gt; Individual diseases</td>
<td>Severe psychological adjustment difficulties Numerical Verbal Scale / HADS test.</td>
</tr>
<tr>
<td>Use of resources</td>
<td>Multi-morbidity</td>
</tr>
<tr>
<td></td>
<td>≥ 3 chronic diseases</td>
</tr>
<tr>
<td></td>
<td>Severe Frailty &amp; Geriatric syndromes</td>
</tr>
<tr>
<td>Use of resources</td>
<td>Charlson test</td>
</tr>
<tr>
<td>Specific-disease indicators</td>
<td>Pressure ulcers, Severe frailty, infections, dysphagia, delirium, falls</td>
</tr>
<tr>
<td></td>
<td>&gt;3 urgent admissions in 6 months</td>
</tr>
<tr>
<td></td>
<td>Increase of demand of care</td>
</tr>
</tbody>
</table>

**FIGURE 1: The NECPAL-WHOCC Tool**

(In red, additions to the PIG/SPCIT tools)
The RADboud indicators of PAlliative Care needs (RADPAC)

<table>
<thead>
<tr>
<th>Description</th>
<th>Details</th>
</tr>
</thead>
</table>
| **Congestive Heart Failure** | 1. The patient has severe limitations, experiences symptoms even while at rest. Mostly bedbound patients. (*NYHA IV*)  
2. There were frequent hospital admissions (> 3 per year)  
3. The patient has frequent exacerbations of severe heart failure (> 3 per year)  
4. The patient is moderately disabled; dependent. Requires considerable assistance and frequent care (*Karnofsky-score ≤ 50%*)  
5. The patient increases in weight what is not responding to increased dose of diuretics  
6. A general deterioration of the clinical situation (oedema, orthopnoea, nycturie, dyspnoea)  
7. The patient mentions 'end of life approaching' |
| **Chronic Obstructive Pulmonary Disease** | 1. The patient is moderately disabled; dependent. Requires considerable assistance and frequent care (*Karnofsky-score ≤ 50%*)  
2. The patient has substantial weight loss (± 10% loss of bodyweight in six months)  
3. The presence of congestive heart failure  
4. The patient has orthopnoea  
5. The patient mentions 'end of life approaching'  
6. There are objective signs of serious dyspnoea (decreased dyspnoea d' effort, dyspnoea with speaking, use of respiratory assistant muscles and orthopnoea) |
| **Cancer** | 1. Patient has a primary tumour with a poor prognosis  
2. Patient is moderately disabled; dependent. Requires considerable assistance and frequent care (*Karnofsky-score ≤ 50%*)  
3. There is a progressive decline in physical functioning  
4. The patient is progressively bedridden  
5. The patient has a diminished food intake  
6. The presence of progressive weight loss  
7. The presence of the anorexia-cachexia syndrome (lack of appetite, general weakness, emaciating, muscular atrophy)  
8. The patient has a diminished 'drive to live' |
Next steps

• Holding statement
• Circulate GPs in European countries thru WONCA Europe

• Produce Guidance /advocacy for use by Primary care and Palliative care organisations to advocate, plan and develop primary palliative care

• WHO model: advocacy, training, services, medication
Statement: The potential of palliative care in the community.

More patients can receive palliative and end-of-life care if it is delivered in the community by Primary Healthcare Teams. For this to happen GPs and nurses working in the community will need training and support by specialist palliative care teams. They will also need adequate time and financial and practical resources.

Primary Care has a great potential to deliver effective palliative care. It can

• Reach patients with all life-threatening illnesses ¹
• Start at diagnosis of life threatening illness ²
• Meet all dimensions of need: physical, social, psychological and spiritual ³
• Provide care in clinics, care homes and at home, and prevent unnecessary hospital admissions ⁴
• Support family carers and provide bereavement care ⁵
Policy
- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
- Essential medicines
  (Policy makers, regulators, WHO, NGOs)

Drug Availability
- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration
  (Pharmacists, drug regulators, law enforcement agents)

Education
- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support
  (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Implementation
- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures
  (Community & clinical leaders, administrators)

(Stjernsward, 2007)
<table>
<thead>
<tr>
<th>Barriers</th>
<th>Frequency of reporting</th>
<th>WHO Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of resources</td>
<td>3</td>
<td>Policy</td>
</tr>
<tr>
<td>Lack of time</td>
<td>2</td>
<td>Policy</td>
</tr>
<tr>
<td>Private medical system</td>
<td>1</td>
<td>Policy</td>
</tr>
<tr>
<td>A law regulating palliative care with euthanasia and assisted suicide</td>
<td>1</td>
<td>Policy</td>
</tr>
<tr>
<td>No national coordination</td>
<td>1</td>
<td>Policy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Opportunities</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Good infrastructure of primary health care</td>
<td>6</td>
<td>Policy</td>
</tr>
<tr>
<td>National strategy</td>
<td>6</td>
<td>Policy</td>
</tr>
<tr>
<td>Increased political pressure</td>
<td>2</td>
<td>Policy</td>
</tr>
<tr>
<td>Reform of the way palliative care is financed</td>
<td>1</td>
<td>Policy</td>
</tr>
<tr>
<td>Reform of the management structures of GPs</td>
<td>1</td>
<td>Policy</td>
</tr>
<tr>
<td>Barriers</td>
<td>Frequency of reporting</td>
<td>WHO Model</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Lack of knowledge and skills among GPs</td>
<td>9</td>
<td>Education</td>
</tr>
<tr>
<td>Poor identification of patients requiring palliative care</td>
<td>4</td>
<td>Education</td>
</tr>
<tr>
<td>Poor public awareness</td>
<td>1</td>
<td>Education</td>
</tr>
<tr>
<td>Limited understanding of the English language</td>
<td>1</td>
<td>Education</td>
</tr>
<tr>
<td>GPs reluctant to talk about palliative care or death and dying with their patients</td>
<td>1</td>
<td>Education</td>
</tr>
<tr>
<td>GPs see only a small number of palliative care patients each year</td>
<td>2</td>
<td>Education</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Opportunities</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased training opportunities available</td>
<td>5</td>
<td>Education</td>
</tr>
<tr>
<td>GPs are available to provide care</td>
<td>4</td>
<td>Education</td>
</tr>
<tr>
<td>90% of the last year of life is spent at home</td>
<td>1</td>
<td>Education</td>
</tr>
<tr>
<td>Increased awareness of importance of palliative care</td>
<td>1</td>
<td>Education</td>
</tr>
<tr>
<td>Conversations about euthanasia can be used to introduce palliative care</td>
<td>1</td>
<td>Education</td>
</tr>
<tr>
<td>Barriers</td>
<td>Frequency of reporting</td>
<td>WHO Model</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Poor handover to out of hours services</td>
<td>2</td>
<td>Implementation</td>
</tr>
<tr>
<td>Financial systems not permitting reimbursements</td>
<td>9</td>
<td>Implementation</td>
</tr>
<tr>
<td>Lack of professional or specialist support</td>
<td>5</td>
<td>Implementation</td>
</tr>
<tr>
<td>Poor structures of primary healthcare teams</td>
<td>4</td>
<td>Implementation</td>
</tr>
<tr>
<td>GPs bypassed by hospital and palliative care teams</td>
<td>2</td>
<td>Implementation</td>
</tr>
<tr>
<td>Part of the population not yet covered by a GP service</td>
<td>1</td>
<td>Implementation</td>
</tr>
<tr>
<td><strong>Opportunities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GPs know the family well</td>
<td>5</td>
<td>Implementation</td>
</tr>
<tr>
<td>The majority of patients want to die at home</td>
<td>1</td>
<td>Implementation</td>
</tr>
<tr>
<td>Availability of out of hours specialist advice for GPs</td>
<td>1</td>
<td>Implementation</td>
</tr>
<tr>
<td>Registered lists of palliative care patients</td>
<td>1</td>
<td>Implementation</td>
</tr>
<tr>
<td>New pathways for palliative care patients</td>
<td>1</td>
<td>Implementation</td>
</tr>
<tr>
<td>Development of a palliative care network</td>
<td>1</td>
<td>Implementation</td>
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<tr>
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<td>Frequency of reporting</td>
<td>WHO Model</td>
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<tr>
<td>--------------------------------------</td>
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</tr>
<tr>
<td>Issues with opiate prescribing</td>
<td>6</td>
<td>Prescribing</td>
</tr>
</tbody>
</table>
Developing palliative care in primary care: a handbook

- Rationale and purpose
- Advocacy within government, GP, pall care,
- Need for education UG, PG, how to support generalists, pub health
- Structures that help: financial, large multi-disciplinary teams, time, continuity of care, OOH care
- Prescribing