The potential of Primary Care to deliver Palliative care


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www.chs.ed.ac.uk/gp/research/ppcrg.php

Chair, International Primary Palliative Care Research group
5 key opportunities in Primary Care in next decade

1. All illnesses
2. Earlier than later
3. All dimensions
4. Community settings
5. All nations
<table>
<thead>
<tr>
<th>Year</th>
<th>Mortality Rate</th>
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<tr>
<td>2005</td>
<td>100%</td>
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<td>2006</td>
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<td>2007</td>
<td>100%</td>
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<td>2008</td>
<td>100%</td>
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Death is part of the human condition.
## Profile of People who die

<table>
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<th>Europe 1900</th>
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</thead>
<tbody>
<tr>
<td>Age at death</td>
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### Top 3 causes
- Infectious diseases
- Accident
- Childbirth

- Disability before death
  - Not much

### 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.

- **Organ failure**: Months or years
- **Cancer**: Weeks, months, years
- **Acute**: 2
- **6**
- **7**: Dementia, frailty and decline
- **GP has 20 deaths per list of 2000 patients per year**

Acute care typically involves conditions that require immediate medical attention, with a shorter duration of care. Palliative care can be provided in all settings, including primary care, hospitals, and at home. The care provided can range from symptom management to psychosocial support, ensuring that patients and their families are well-informed and supported throughout the illness.
“Acute decline” Trajectory, Diagnosis to Death

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

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

Function

High

Low

Frequent admissions, self-care becomes difficult

Time

Death

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

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

Function

Onset deficits in activities of daily living, speech, ambulation

Time

Variable - up to 6-8 years

Death

High

Low

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)

Function:

- High
- Low

Time:

Death

Multi-morbidities normal

Primary care can integrate curative and palliative care earlier rather than later.

Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Stage 3  Terminal care

Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Sentinel events

Care Plan

Gold standards Framework

Stage 3  Terminal care

Liverpool Care Pathway

Time

Death
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* ”

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

#### Heart disease
- NYHA Class III/IV heart failure, severe valve disease or extensive coronary artery disease.
- Breathless or chest pain at rest or on minimal exertion.
- Persistent symptoms despite optimal tolerated therapy.
- Systolic blood pressure < 100mmHg and/or pulse > 100.
- Renal impairment (eGFR < 30 ml/min).
- Cardiac cachexia.
- Two or more acute episodes needing intravenous therapy in past 6 months.

#### Respiratory disease
- Severe airways obstruction (FEV1 < 30%) or restrictive deficit (vital capacity < 60%, transfer factor < 40%).
- Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).
- Breathless at rest or on minimal exertion between exacerbations.
- Persistent severe symptoms despite optimal tolerated therapy.
- Symptomatic right heart failure.
- Low body mass index (< 21).
- More emergency admissions (> 3) for infective exacerbations or respiratory failure in past year.

#### Cancer
- Performance status deteriorating due to metastatic cancer and/or co-morbidities.
- Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.

#### Neurological disease
- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Symptoms which are complex and difficult to control.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

#### Dementia
- Unable to dress, walk or eat without assistance; unable to communicate meaningfully.
- Worsening eating problems (dysphagia or dementia related) - now needing pureed/soft diet or supplements.
- Recurrent febrile episodes or infections; aspiration pneumonia.
- Urinary and faecal incontinence.

#### Kidney disease
- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).
- Conservative kidney management due to multi-morbidity.
- Deteriorating on renal replacement therapy with persistent symptoms and/or increasing dependency.
- Not starting dialysis following failure of a renal transplant.
- Now life limiting condition or kidney failure as a complication of another condition or treatment.

#### Liver disease
- Advanced cirrhosis with one or more complications:
  - intractable ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Serum albumin < 25g/l and prothrombin time raised or INR prolonged (INR > 2).
- Hepatocellular carcinoma.
- Not fit for liver transplant.

### SPICT: supportive and palliative care indicator tool

#### 1. Ask

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes/No</th>
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<tbody>
<tr>
<td>Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness?</td>
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<tr>
<td>Would you be surprised if this patient died in the next 6-12 months?</td>
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</table>

#### 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>
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<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>
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<td>Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.</td>
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<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
<td>Breathless at rest or on minimal exertion between exacerbations.</td>
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<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Neurological disease</td>
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3. Meeting all dimensions of need

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<tbody>
<tr>
<td>social</td>
<td>spiritual</td>
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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"

"great nurses and departments they are so caring"

"It was like a black hole"

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

"It’s much worse the second time round"

Trajectories

- Physical
- Social
- Psychological
- Spiritual

Diagnosis, Recurrence, Return home, Terminal Stage

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

Keri Thomas

Geoff Mitchell
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
• Montreal Oct 2012
Community based: care frameworks

Steps:

1. Identify
2. Assess
3. Plan

+ communicate
Patient has duplicate NHS numbers. Click here to see other entries.

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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: decision support intranet pages](#)

**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.
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?


Community hospice team
Primary care teams

Deirdra Sives
Bruce Mason
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
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 admissions to hospital
- 92% of residents of nursing homes die there
- Interviewed bereaved relatives reported better care
Out of Hours Care in Lothian
BJGP 2006
Health promoting palliative care

Living & Dying in Style

Dr. Eric Fairbank
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.
Outline comparison

Edinburgh, Scotland

- main issue existential or spiritual distress
- analgesia effective
- anger in the face of illness
- “just keep it to myself”
- spiritual needs evident but unmet

Chogoria, Kenya

- main issue physical suffering, especially pain
- analgesia unaffordable
- acceptance rather than anger
- community support
- patients comforted and inspired by belief in God
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)
NAIROBI: THEY CAME FROM 30 COUNTRIES!
Integrate pall care in primary care

- Curative plus preventive plus palliative
- Morphine prescribing by community nurses in Africa
- What are the basic palliative care skills needed in primary care internationally
5 key roles

1. All illnesses
2. Earlier than later
3. All dimensions
4. All settings
5. All nations
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 “palliative care approach”

- 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
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

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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 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.

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www.edinburgh-inspiringcapital.com

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www.lifelong.ed.ac.uk/palliativecare

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

Palliative approach is just good general practice: all 4 aspects, curing and caring, and thinking ahead